

Is it a patch or a disability? Recognising the early signs of leprosy and late case detection in a low-endemic area of Benin: a cross-sectional study

Fifamin Noël Christelle GBAGUIDI

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Sètondji Diane ZANVO

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Sèdjro Gimatal Esaï ANAGONOU

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Yévèdo Borel TOSSOU

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Karine Lucrèce Marie CODJO-SEIGNON

karineseignon@yahoo.fr

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Sonagnon Inès Elvire AGBO

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Jean Gabin HOUZO

Centre Interfacultaire de Formation et de Recherche en Environnement pour le Développement Durable (CIFRED), Université d'Abomey-Calavi, Benin

Bédié VIGNON

Institut Régional de Santé Publique de Ouidah, Université d'Abomey-Calavi, Benin

Cristina JUAN JIMENEZ

Fondation Anesvad, Bilbao, Spain.

Alice TOUSSAINT

Fondation Raoul Follereau, France

Pierre VELUT

Fondation Raoul Follereau, France

Anil FASTENAU

German Leprosy and Tuberculosis Relief Association (DAHWA), Würzburg, Germany

Anna GINE-MARCH

Fondation Anesvad, Bilbao, Spain.

Armelle Sabine Yélignan HOUNKPATIN

Université Nationale des Sciences, Technologies, Ingénierie et Mathématiques, Benin

Roch Christian JOHNSON

Fondation Raoul Follereau, France

Article

Keywords: leprosy, early case detection, grade 2 disability, multibacillary leprosy, illness representations, knowledge, attitudes, low endemicity, Benin

Posted Date: September 2nd, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-10720958/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Although Benin reports fewer than 100 new leprosy cases per year, 47–54% of those notified between 2022 and 2025 had grade 2 disability (G2D) at diagnosis. We examined whether affected individuals and their neighbours recognised the disease by its early signs, such as insensitive skin patches, or by its perceived late consequences.

Methods

An analytical cross-sectional study was conducted in the Plateau and Zou departments of Benin among 175 people with multibacillary leprosy (64.1% of 273 cases registered there in 2013–2023) and 746 residents randomly selected within 100 m of the patients' homes. Because the diagnosis was never disclosed, residents were analysed as members of endemic rural communities rather than as traced contacts, with no claim of representativeness. Recognition of early signs was compared with the perception of late consequences, and associations with G2D were examined using logistic regression.

Results

Among residents, 66.9% had heard of leprosy. Among those aware, 62.5% cited death, whereas the insensitive patch (45.5%) and disability or impairment (47.5%) were cited at indistinguishable rates; across all residents, only 30.4% could name this early sign. G2D was recorded in 33.7% of affected individuals: 19.4% of those presenting with a patch, 50.0% with sensory loss and 80.0% with visible disability. Compared with presentation for a patch, presentation for sensory loss was associated with higher odds of G2D (adjusted odds ratio (aOR) 3.85, 95% confidence interval (CI) 1.64–9.05). No difference was observed between actively and passively detected cases (36.1% versus 33.1%; OR 1.14, 95% CI 0.53–2.46), a comparison limited by only 36 active cases. In principle, 96.4% of residents would accept preventive medication; however, acceptance fell to 73.9% once distance, time and side effects were taken into account.

Conclusions

In these low-endemic rural communities, leprosy was more evident through its perceived late consequences than its initial manifestations, and disability at diagnosis tracked the stage at which patients entered care. The findings support communication centred on persistent patches with altered sensation, reinforced recognition skills among first-line workers, and integration of education with case finding and contact-based prevention. The observational design precludes causal inference.

Background

Benin has become a low-endemic country for leprosy. Between 2012 and 2021, the number of new cases reported nationwide decreased by around two-thirds, falling from 253 to 77. During this period, the rate

of new cases detected per 100,000 people declined by an average of 0.22 each year, falling from 2.70 to 0.61. However, the decline has since levelled off, with between 59 and 87 new cases notified annually from 2022 to 2025, at a detection rate of between 0.46 and 0.59 per 100,000 (see Table 1). Currently, fewer than a hundred cases are notified annually for a national population of around 14 million, and the disease is no longer a familiar presence in community life [1–4].

Table 1
Leprosy notification and grade 2 disability at diagnosis, Benin, 2022–2025.

Year	New cases	Rate per 100,000	Multibacillary n (%)	G2D n (%)	G2D rate per million
2022	59	0.46	57 (97)	32 (54)	2.48
2023	75	0.57	70 (93)	35 (47)	2.64
2024	74	0.53	66 (89)	39 (53)	3.00
2025	87	0.59	75 (86)	42 (48)	2.84
<i>G2D: grade 2 disability. Between 2012 and 2021 the number of new cases notified nationally fell from 253 to 77 and the detection rate from 2.70 to 0.61 per 100,000; the table covers the period since that decline levelled off. Detection rates were computed from the notified case counts and the national population denominators used by the programme. Sources: WHO global leprosy updates in the Weekly Epidemiological Record for the 2022, 2023 and 2024 data [1–3]; National Leprosy and Buruli Ulcer Control Programme (PNLLUB) annual monitoring reports for the 2025 data and for all departmental figures [4], the 2025 data not yet having appeared in the Weekly Epidemiological Record.</i>					

However, this success has not translated into earlier diagnosis. Close to half of all new cases in Benin are reported with grade 2 disability, i.e. visible impairment of the hands, feet or eyes: 47–54% each year from 2022 to 2025, with no downward trend (Table 1). In fact, the proportion has been rising for two decades, increasing from 21.2% in 2006 to 32% in 2018. Over the same period, the proportion of new cases that were multibacillary rose from 73% to 90% [5]. Throughout this period, the grade 2 disability rate has remained between 2.5 and 3.0 per million people, two to three times the global rate of 1.2 per million reported in 2023 [2], even though the global strategy Towards Zero Leprosy 2021–2030 calls for a 90% reduction in this rate by 2030 [6]. This plateau has persisted despite sustained active case finding through integrated skin campaigns, contact screening and post-exposure prophylaxis in the most endemic districts. Grade 2 disability at diagnosis is the standard marker of delayed detection [6–8] since it only develops after prolonged, untreated nerve damage.

Low endemicity may itself work against early detection. As cases become rarer, first-hand exposure to leprosy in its early, unremarkable form disappears from collective experience, while memories of the disease survive through its most visible and stigmatising outcome: deformity [9]. If a community associates leprosy with mutilation rather than an insensitive patch on the skin, an insensitive patch will not prompt anyone to visit a health centre. Active screening teams then encounter populations who cannot identify the disease in themselves, resulting in detection only at the disability stage.

Two Beninese studies already suggest this. A national study of 254 registered patients found grade 2 disability in 58.3% of cases, with a median interval of 36 months between the first symptom and a confirmed diagnosis [10]. The factors associated with late screening were stigma, care-seeking pathways and the difficulty that health workers themselves had in recognising the disease. Among 394 contacts in four endemic districts of Zou and Plateau, three-quarters recognised leprosy by its visible deformities, but 99.2% could not describe any of the initial signs [11]. However, neither study related the stage at which a patient was diagnosed to the symptoms they presented with. More broadly, surveys on leprosy usually report the proportion of respondents citing each item [12, 13]. They seldom compare the recognition of early signs with the citation of late consequences within the same respondents and rarely link the reason a patient came to the clinic with whether they were detected late.

Late detection, as measured by the proportion of new cases with grade 2 disability, is therefore an established feature of the programme rather than a hypothesis to be tested. It is documented by four consecutive years of national surveillance across all notified cases, independently of the present sample. This study investigated two possible contributors: the stage at which patients enter the health system, and whether the surrounding population possesses the knowledge that would enable earlier entry. Specifically, the study aimed to: (i) compare recognition of an insensitive skin patch with citation of disability and death among affected persons and neighbourhood residents; (ii) identify factors associated with failure to recognise the early sign; (iii) examine whether the sign prompting consultation was associated with G2D at diagnosis; and (iv) describe acceptance of post-exposure preventive medication among neighbourhood residents, which does not depend on the population's ability to recognise the disease.

Methods

Study design and setting

This was an analytical, cross-sectional study conducted in the Plateau and Zou departments in southern Benin. These two departments, together with Atacora, have been the three most endemic in the country over the past two decades. They accounted for 17.2% and 18.8%, respectively, of national cases between 2012 and 2021, and 22.4% and 19.3% of the 295 new cases notified nationally between 2022 and 2025. Both departments have a high rate of late detection: grade 2 disability was recorded in 60.6% (40/66) of new cases in Plateau and 40.4% (23/57) in Zou over those four years.

Data were collected between 29 October 2024 and 28 February 2025 at the participants' places of residence, which were located using GPS coordinates recorded in the field. Recruitment was register-based rather than centre-based, which is important when our estimates are compared with those of studies recruiting in treatment centres. This study was conducted as part of the 2PEP4LEP project, a feasibility and effectiveness study investigating the combined use of integrated screening for neglected tropical diseases and single double-dose rifampicin post-exposure prophylaxis (SDDR-PEP) in Benin and Côte d'Ivoire. The data collection tools were developed and pre-tested, and the interviewers recruited and

trained, before fieldwork began. Reporting follows the STROBE statement for cross-sectional studies [14].

Population and sampling

Persons affected by leprosy were identified from the registers of the Programme National de Lutte contre la Lèpre et l'Ulcère de Buruli (PNLLUB) for the period 2013–2023, during which time programme records were complete and reliable. Only cases classified as multibacillary (MB) at diagnosis, that is, cases presenting with five or more skin patches according to the WHO field classification [7], were eligible. Consequently, the sample is homogeneous in terms of bacillary load, with no paucibacillary (PB) cases represented. The location of each registered case was determined using GPS coordinates recorded on site and plotted as a track in GPX Viewer.

No sampling was applied to affected persons; every MB case registered in the two departments between 2013 and 2023 was eligible and sought. Persons with a major mental disorder likely to compromise participation or the validity of consent were not eligible. No age threshold was applied to affected persons, given their direct experience of the disease. Of the 273 cases identified (163 in Plateau and 110 in Zou), 98 could not be included: 47 had moved away (41 in Plateau and 6 in Zou), 50 had died (39 in Plateau and 11 in Zou), and one person was unable to complete the interview due to communication difficulties (Zou). The questionnaire was therefore administered to the remaining 175 cases: 83 of the 163 cases registered in Plateau (50.9%) and 92 of the 110 cases registered in Zou (83.6%). None of those approached refused to participate, giving an overall participation rate of 64.1% (Fig. 1).

Neighbourhood residents were defined as individuals aged 14 years or older who lived within a 100 m radius of a registered case, including those who shared the same dwelling or courtyard. The sampling frame was therefore geographical, ranging from household members to unrelated neighbours in whatever proportion the local settlement pattern produced. For each enrolled case, eligible residents were identified using the trackbook function of GPX Viewer, and then selected by simple random sampling in R. This ensured that at least one resident was selected for each case, with a fixed sampling fraction.

The identity and diagnosis of the registered case were never revealed during recruitment. Leprosy is generally kept confidential in these communities, so respondents were unaware that they were being approached in relation to someone affected by the disease. Consequently, residents were analysed as individual members of endemic rural communities and not as contacts of a known case. The limitations of this design choice are set out in the 'Limitations' section.

The resulting sample was widely dispersed; the 746 residents were spread over 325 villages or hamlets. Of these, 165 (50.8%) contributed a single respondent, while only 24 contributed six or more.

Variables and measures

Knowledge was explored first through awareness of the disease. Among those who were aware, we recorded the causes cited (including supernatural attributions such as witchcraft, divine punishment or curses), the early signs, transmission routes and treatment modalities cited, and the perceived complications of the disease. Failure to recognise the early sign was defined as an inability to cite an insensitive skin patch. For the population-level analysis, residents who had never heard of leprosy were also considered unable to recognise the early sign, and were therefore included in this category. This gave a total of 519 out of 746 residents (69.6%). This indicator is deliberately more stringent than the citation of any early sign. As the categories 'disability' and 'impairment' overlap in everyday speech, a combined indicator (disability or impairment, any) is reported alongside its two components.

Attitudes were assessed on the basis of willingness to engage with control activities (accepting examination, helping to detect cases and supporting control measures) and acceptance of cohabiting with a person with leprosy. Knowledge and attitude items were administered to 499 out of 746 residents who reported having heard of leprosy and to 172 out of 175 affected persons. Two residents who had never heard of leprosy nevertheless completed the attitude module owing to a failure of the questionnaire's skip logic. These two respondents were excluded since the attitude items presuppose some knowledge of the disease, and they provided no knowledge-module data. The attitude analyses therefore rest on 499 residents.

For affected individuals, the symptom that prompted the consultation leading to diagnosis was recorded (e.g. insensitive patch, sensory loss, visible G2D, other). Where several symptoms were reported, participants were classified by the most advanced symptom. Practice was measured by the proportion of participants who reported recourse to a traditional healer among the sources of care used after diagnosis. Acceptance of post-exposure chemoprophylaxis was assessed among all 746 neighbourhood residents, including the 247 who had never heard of leprosy. Robust acceptance was defined as acceptance that was maintained despite the three constraints a person actually faces when prophylaxis is delivered in the field: travelling more than 5 km to receive the treatment, losing a whole day from work to do so, and experiencing the side effects of the first dose, chiefly discoloured urine. G2D at diagnosis was taken from the PNLLUB records rather than from participants (see below).

The detection mode was recorded during the interview as a single questionnaire item with two response options: 'passive', where the participant had gone to the health centre of their own accord; and 'active', where the case had been found by a health worker during a screening activity.

Late detection was defined, in line with WHO practice, as the presence of grade 2 disability (G2D) at diagnosis, i.e. visible impairment of the hands, feet or eyes. Disability grading was performed and recorded at diagnosis by nurses from the national programme. For the present study, the interviewer transcribed it from the participant's PNLLUB record during the home visit. Grade 2 disability is, by definition, a visible impairment and was therefore confirmed by direct observation at that visit. The participant was never asked about it, so the outcome is a clinical assessment made at the time of diagnosis rather than anything recalled during the interview. Care-seeking delay, recorded separately as

the number of months between the first symptoms appearing and the first contact with a health worker, was used to assess the convergent validity of this indicator, rather than being a component of it.

Data collection

Data were collected by ten interviewers, each holding a bachelor's degree in sociology or environment and health. The interviewers worked under two supervisors and used a structured questionnaire administered face-to-face with ODK Collect. The questionnaire was administered in Fon and Nagot, the local languages of the study areas. Training lasted ten days and combined instruction on the collection tools with pre-testing in Zou and Plateau, incorporating the resulting observations. The final version of the tools was validated by the national ethics committee. Fieldwork was supervised throughout, and the team met at the end of each day to review the collected questionnaires and resolve any inconsistencies. Interviews lasted 90 minutes on average.

Sample size and precision

The number of neighbourhood residents was determined a priori using the Schwartz formula, assuming the most conservative expected proportion (50%), an absolute precision of 4 percentage points and an alpha risk of 5%. This gave a target of 601 residents, increased by 15% to allow for non-response, giving a total of 692. In the event, 746 residents were enumerated and interviewed: 403 in Plateau and 343 in Zou. No calculation was performed for the affected persons, whose number was determined by the number of MB cases registered in the two departments between 2013 and 2023 who were available for interview.

The precision achieved with these sample sizes is as follows: the 95% confidence interval half-width is approximately 3 percentage points for proportions estimated from all 746 residents, 4.4 points for proportions estimated from the 499 informed residents and 7.0 points for G2D among the 175 affected individuals. The comparison of actively and passively detected cases is based on 36 and 139 patients, respectively, and is therefore reported as imprecise rather than negative. With 59 G2D events, multivariable models on affected individuals were limited to a maximum of six parameters, corresponding to approximately ten events per parameter.

Statistical analysis

Categorical variables were described as counts and percentages. Associations between sociodemographic factors and each outcome (failure to cite the insensitive patch, refusal to cohabit, use of a traditional healer and G2D at diagnosis) were first assessed using bivariate logistic regression. Bivariate associations are reported in the text.

Covariates were specified a priori on a conceptual basis rather than being selected on the basis of bivariate significance. The covariates were: age, sex, education, occupation, marital status, residence

and department for models on residents; and age, sex, education, marital status, department and time since diagnosis for models on affected individuals. The detection mode was added to the presenting sign model. Age was dichotomised at 16 years. The 15-year threshold used elsewhere to describe the sample could not be used in the models as all nine residents under the age of 15 failed to cite the insensitive patch; this cut-point therefore separates the data completely and cannot be estimated in a logistic model.

The results are reported as odds ratios (OR) with 95% confidence intervals, and global Wald or likelihood-ratio tests are provided for each categorical variable. As several of the studied outcomes are common in this population (in particular, failure to cite the insensitive patch [69.6%] and refusal of cohabitation [77.6%]), odds ratios are interpreted as ratios of odds rather than approximations of risk ratios. Knowledge and delay, as measured around or after diagnosis, were excluded from causal interpretations of G2D because of concerns regarding reverse causality and recall. Three out-of-range codes for care-seeking delay (999 months in two records and 9999 in one) were treated as missing. No other missing values were recorded for any analysed variable in either group. Among neighbourhood residents, the only blank fields were the conditional items on distance, time and side effects. These were not put to the 27 individuals who declined the medicine in principle. Among affected individuals, three participants left the entire knowledge, attitude and practice block unanswered, which is why those analyses rest on 172 individuals; the same three participants had no recorded care-seeking delay, so that variable was available for 169 of the 175 affected individuals. No imputation was performed, and every model was fitted using complete records. Significance was set at 0.05 and no formal adjustment for multiple comparisons was applied; therefore, *P*-values close to this threshold should be considered exploratory.

Calibration was assessed using the Hosmer–Lemeshow test, and discrimination was assessed using the area under the receiver operating characteristic curve, which is reported as apparent discrimination, since it was obtained from the data used for fitting. Some categories were small, particularly the ten patients who sought help for a visible disability, and the corresponding estimates are imprecise. The intraclass correlation by village was low for each principal outcome (0.05 to 0.15; design effect: 1.07 to 1.19), but this did not alter any conclusions. Data were exported to Excel and analysed using IBM SPSS Statistics version 26.

Ethics

The protocol was approved by the National Ethics Committee for Health Research of Benin (Ref. CNERS 011/2024). The favourable opinion took effect on 15 October 2024, before any activities involving participants took place. The preparatory step in September 2024 consisted solely of assembling the sampling frame from existing programme records. The study was conducted in accordance with the Declaration of Helsinki. Participation was voluntary, and written informed consent was obtained from all participants. For those under 18, parental consent and the minor's own assent were obtained, and a fingerprint was taken in the presence of an independent witness for illiterate participants. Confidentiality and anonymity were respected throughout.

Results

Participants

A total of 175 individuals affected by MB disease were included in the study, representing 64.1% of the 273 MB cases registered in the two departments between 2013 and 2023. Additionally, 746 neighbourhood residents were included (Fig. 1). Both groups were predominantly adults (≥ 15 years: 98.3% and 98.8%) living in rural areas (96.0% and 92.0%). Affected individuals had lower levels of formal education than neighbourhood residents (73.7% had no formal education versus 59.4%), and a higher proportion were farmers (70.9% versus 62.7%). Men slightly outnumbered women among affected persons (53.1% versus 46.9%), whereas most of the residents interviewed were women (57.8%). Widowhood was more prevalent among affected individuals (17.1% versus 7.8%) (Table 2).

Table 2
Sociodemographic characteristics of affected persons and neighbourhood residents, Benin.

Characteristic	Affected persons (n = 175) n (%)	Neighbourhood residents (n = 746) n (%)
Age group		
< 15 years	3 (1.7)	9 (1.2)
≥ 15 years	172 (98.3)	737 (98.8)
Sex		
Female	82 (46.9)	431 (57.8)
Male	93 (53.1)	315 (42.2)
Occupation		
Casual worker or other	17 (9.7)	30 (4.0)
Pupil / student	1 (0.6)	33 (4.4)
Trader	12 (6.9)	90 (12.1)
Craftsperson	21 (12.0)	125 (16.8)
Farmer	124 (70.9)	468 (62.7)
Education		
None	129 (73.7)	443 (59.4)
Primary	36 (20.6)	184 (24.7)
Secondary or higher	10 (5.7)	119 (16.0)
Marital status		
Single	18 (10.3)	121 (16.2)
Divorced / separated	12 (6.9)	9 (1.2)
Married / cohabiting	115 (65.7)	558 (74.8)
Widowed	30 (17.1)	58 (7.8)
Residence		
Rural	168 (96.0)	686 (92.0)

All counts re-computed from the source databases. The lower age limit for residents was 14 years; the “< 15 years” stratum therefore contains only respondents aged 14. Casual workers and the “other” occupational category were combined, as were secondary and tertiary education, because of small cell sizes; this grouping is applied consistently throughout the analyses. Recruitment and non-inclusion figures previously shown in this table are given in Fig. 1 to avoid duplication.

Characteristic	Affected persons (n = 175) n (%)	Neighbourhood residents (n = 746) n (%)
Age group		
Urban	7 (4.0)	60 (8.0)
Department		
Plateau	83 (47.4)	403 (54.0)
Zou	92 (52.6)	343 (46.0)
Mean age (years)	45.8	37.6
Villages or hamlets of residence	157	325 (165 with a single respondent; range 1–17)
<i>All counts re-computed from the source databases. The lower age limit for residents was 14 years; the “< 15 years” stratum therefore contains only respondents aged 14. Casual workers and the “other” occupational category were combined, as were secondary and tertiary education, because of small cell sizes; this grouping is applied consistently throughout the analyses. Recruitment and non-inclusion figures previously shown in this table are given in Fig. 1 to avoid duplication.</i>		

Leprosy knowledge

Two-thirds of neighbourhood residents (66.9%) had heard of leprosy. Of those who were aware of it, 25.5% of residents and 35.5% of affected persons attributed it to supernatural causes.

The central comparison concerns what respondents associated with the disease. Among neighbourhood residents who knew of leprosy, death was by far the most frequently named consequence, cited by 62.5%, compared with 45.5% who cited an insensitive patch. Disability was cited by 45.3% of respondents, a figure that rises to 47.5% when disability and impairment are combined, a rate indistinguishable from that of the patch. At a population level, the decisive figure is that only 30.4% (227/746) of the entire resident sample could name the early sign, while 69.6% (519/746) could not. Almost one in four aware residents (23.0%) named a disability or impairment without mentioning the insensitive patch, while 21.0% mentioned the patch without mentioning either. Among affected persons, however, the balance was reversed, with the insensitive patch being cited by 77.9%. Using the less stringent criterion of citing any early sign, 58.7% of residents (438 out of 746) failed to do so.

Knowledge of early signs remained limited in both groups. Beyond the patch, neurological signs (e.g. sensory loss and enlarged nerves) were recognised by fewer than one in five affected individuals and fewer than one in ten residents. While medical treatment was widely recognised (95.9% of affected individuals and 79.6% of residents), traditional treatment was still cited by approximately one in six respondents. Only a small minority named a microbial agent as the transmission mechanism (5.8% and 3.4%), whereas direct contact and contaminated objects were more often cited (Table 3). Overall, 60.7% of residents and 51.7% of affected individuals could not name a cause of leprosy and 42.9% and 47.1%, respectively, could not name a transmission route.

Table 3
Knowledge of leprosy among affected persons and neighbourhood residents, Benin.

Knowledge item	Affected persons n (%)	Neighbourhood residents n (%)
Ever heard of leprosy	n = 175	n = 746
Yes	not asked*	499 (66.9)
Causes cited	n = 172	n = 499
Witchcraft / spell	61 (35.5)	127 (25.5)
Divine punishment / curse	8 (4.7)	14 (2.8)
Poor hygiene and sanitation	19 (11.0)	49 (9.8)
Does not know	89 (51.7)	303 (60.7)
Early signs cited	n = 172	n = 499
Insensitive skin patch	134 (77.9)	227 (45.5)
Sensory disturbance	36 (20.9)	31 (6.2)
Combined skin and nerve signs	19 (11.0)	21 (4.2)
Enlarged nerves	10 (5.8)	31 (6.2)
Does not know	0 (0.0)	191 (38.3)
Transmission routes cited	n = 172	n = 499
Direct contact with a patient	50 (29.1)	226 (45.3)
Airborne	7 (4.1)	5 (1.0)
Microbes	10 (5.8)	17 (3.4)
Contaminated objects	27 (15.7)	114 (22.8)
Occult route	14 (8.1)	26 (5.2)
Does not know	81 (47.1)	214 (42.9)
Treatment modalities cited	n = 172	n = 499
Medical	165 (95.9)	397 (79.6)
Traditional	29 (16.9)	90 (18.0)

*Multiple answers possible per item; all counts verified against the source databases. Items labelled perceived consequences record what respondents associate with leprosy and are not a clinical inventory of its complications: leprosy is not in itself a fatal disease, and the citation of death is reported as a marker of perceived severity. The combined disability-or-impairment row is the figure quoted in the abstract and discussion; its two components overlap. * The leprosy-awareness question was administered to residents only; among affected persons, three participants did not answer the knowledge module and are excluded from the denominator of 172.*

Knowledge item	Affected persons n (%)	Neighbourhood residents n (%)
Spiritual	3 (1.7)	4 (0.8)
Self-medication	7 (4.1)	3 (0.6)
Does not know	0 (0.0)	80 (16.0)
Perceived consequences cited	n = 172	n = 499
Death	117 (68.0)	312 (62.5)
Disability	105 (61.0)	226 (45.3)
Impairment	43 (25.0)	54 (10.8)
Disability or impairment (any)	113 (65.7)	237 (47.5)
<i>Multiple answers possible per item; all counts verified against the source databases. Items labelled perceived consequences record what respondents associate with leprosy and are not a clinical inventory of its complications: leprosy is not in itself a fatal disease, and the citation of death is reported as a marker of perceived severity. The combined disability-or-impairment row is the figure quoted in the abstract and discussion; its two components overlap. * The leprosy-awareness question was administered to residents only; among affected persons, three participants did not answer the knowledge module and are excluded from the denominator of 172.</i>		

Factors associated with failure to cite the insensitive patch among neighbourhood residents

In the bivariate analysis, the following factors were associated with failure to cite the insensitive patch: sex, age group, occupation, education and marital status, whereas residence and department were not (see Table 4). After adjusting for all seven pre-specified covariates, male sex was associated with 59% lower odds of failing to cite the patch (adjusted odds ratio (aOR) 0.41; 95% confidence interval (CI) 0.28–0.60), and craftspeople were the only occupational group with significantly higher odds (aOR 3.06; 95% CI 1.18–7.96). Married and widowed respondents were less likely than single respondents to fail to cite the early sign. Residents of Zou were marginally less likely to fail than those of Plateau (aOR 0.68; 95% CI 0.47–0.97), an association that was not evident in the bivariate analysis. Age group, education and residence were not associated with the outcome in the global tests, and their inclusion left the other estimates essentially unchanged. Within the education variable, the contrast between primary schooling and no schooling reached nominal significance in the direction of poorer recognition (aOR 1.63; 95% CI 1.04–2.56). However, the effect was not graded, and the global test was not significant; therefore, this isolated contrast is not interpreted.

Table 4

Factors associated with failure to cite the insensitive patch among neighbourhood residents (n = 746; 519 events), multivariable logistic regression.

Factor (reference)	Adjusted OR	95% CI	P
Male sex (female)	0.41	0.28–0.60	< 0.001
Occupation (casual worker or other)			0.004
Pupil / student	0.31	0.06–1.48	
Trader	1.60	0.61–4.20	
Craftsperson	3.06	1.18–7.96	
Farmer	1.77	0.75–4.16	
Marital status (single)			< 0.001
Divorced / separated	0.12	0.02–0.74	
Married / cohabiting	0.09	0.03–0.27	
Widowed	0.05	0.01–0.15	
Department: Zou (Plateau)	0.68	0.47–0.97	0.035
Age group: ≥ 16 years (< 16)	0.34	0.07–1.74	0.160
Education (none)			0.085
Primary	1.63	1.04–2.56	
Secondary or higher	1.07	0.61–1.88	
Residence: urban (rural)	1.79	0.87–3.69	0.105

Outcome: inability to cite an insensitive skin patch, among all 746 residents, those who had never heard of leprosy being classified as unable. All seven a priori covariates are included; p values are likelihood-ratio tests for each variable. The age variable is dichotomised at 16 years rather than at the 15 years used in Table 2, because all 9 residents aged under 15 failed to cite the patch, which separates the data completely and makes a 15-year cut-point inestimable. The marital-status estimates are strongly confounded by age: single respondents are structurally younger and include the residents aged under 15 and most students, so their magnitude is larger than a social variable of this kind would plausibly produce and they are better read as a marker of age and life stage than as an effect of conjugal stability. The departmental difference was absent in bivariate analysis, is of marginal statistical significance and concerns a variable that varies between localities rather than between individuals; it should not be given substantive weight.

Attitudes: engagement and social distance

Willingness to engage with control activities was high and consistent: among respondents who had heard of leprosy, 88.6% of residents (442/499) held all three favourable dispositions, accepting examination, helping to detect cases, and supporting control, and 96.5% of affected individuals

(166/172) endorsed both applicable items. There were no sociodemographic determinants among residents.

Acceptance of everyday proximity diverged sharply between the two groups. Among residents, 22.4% (112/499) would agree to live with someone with leprosy; 77.6% (387/499) refused. Among affected individuals, the pattern was reversed: 77.9% (134/172) would accept, while 22.1% would not. Among residents, sex was the only factor retained in the multivariable model: men refused less often than women (aOR: 0.58; 95% CI: 0.36–0.95). Among affected individuals, no sociodemographic factor was significantly associated with refusal (marital status: married versus single, OR 0.51, 95% CI 0.15–1.78).

One disposition stood apart: 95.0% of residents who had heard of leprosy (474/499) agreed to be examined by a healthcare professional. This included 93.0% of those who were unable to identify the insensitive patch, and 95.1% of those who refused to live with a patient. There were no sociodemographic determinants of refusal.

Practices: care-seeking pathways

Around one affected person in six (18.0%, 31/172) reported having received care from a traditional healer during or after treatment. Sex was the only associated factor ($P = 0.033$): men had 58% lower odds of such a consultation than women (OR 0.42; 95% CI 0.19–0.93). No other sociodemographic variable was associated with this practice (occupation: $P = 0.397$; education: $P = 0.311$; marital status: $P = 0.796$; residence: $P = 0.443$).

Acceptance of preventive medication

Willingness to take medicine to avoid contracting leprosy was almost universal: 719 out of 746 residents (96.4%) agreed (see Table 5). Consent was not significantly associated with knowledge of the disease. Consent reached 93.5% among the 247 residents who had never heard of leprosy and 95.8% among those who were unable to identify an insensitive patch. This figure was statistically indistinguishable from the 97.8% observed among those who could identify an insensitive patch (adjusted OR 2.04; 95% CI 0.75–5.52; $P = 0.16$). Stigmatising attitudes did not stand in the way either: 97.9% of residents who refused to cohabit with someone with leprosy would nevertheless accept the medicine. Neither sex nor education level was associated with refusal. The 27 refusals were almost all justified by the same reasoning: one does not take medicine for a disease one does not have. As there were so few refusals, the analyses of baseline acceptance have limited power and are reported as descriptive.

Table 5

Acceptance of post-exposure chemoprophylaxis among neighbourhood residents (n = 746), overall and by recognition of the early sign.

Acceptance item	Denominator	n (%)	Knows early sign	Does not know
Would accept a preventive medicine	746	719 (96.4)	222/227 (97.8)	497/519 (95.8)
Would travel > 5 km	719	644 (89.6)	91.9%	88.5%
Would devote a whole day	719	625 (86.9)	90.1%	85.5%
Would continue despite side effects	719	630 (87.6)	94.6%	84.5%
Would encourage others to take it	719	682 (94.9)	—	—
Robust acceptance (all three constraints)	746	551 (73.9)	187/227 (82.4)	364/519 (70.1)
Preferred form: tablet	719	420 (58.4)	—	—
Preferred form: any form	719	292 (40.6)	—	—
<i>A denominator column has been added because the items do not share the same base: rows with a denominator of 719 concern the residents willing in principle, whereas rows with a denominator of 746 concern the whole resident sample. Baseline acceptance did not differ by recognition of the early sign (crude $P = 0.25$; adjusted OR 2.04, 95% CI 0.75–5.52, $P = 0.16$); robust acceptance did ($P < 0.001$). The module was administered to all 746 residents, including the 247 who had never heard of leprosy.</i>				

Acceptance became conditional as soon as the offer carried a cost. Among those who were willing in principle, 89.6% would travel more than 5 km, 86.9% would devote a whole day, and 87.6% would continue taking the medicine despite experiencing side effects from the first dose. Overall, 73.9% of the sample (551 out of 746) maintained their acceptance when faced with all three constraints. Unlike baseline consent, this robust acceptance depended on knowledge; 82.4% of residents could name the insensitive patch, compared with 70.1% of those who could not ($P < 0.001$). This association persisted after adjusting for sex, education, marital status and department (aOR 1.67; 95% CI 1.11–2.50; $P = 0.014$). The constraint that discriminated most strongly was tolerance of side effects (94.6% versus 84.5%; $P < 0.001$), whereas distance and time did not differ significantly by knowledge. Respondents who were married or widowed were also more likely to maintain acceptance than those who were single (aOR: 2.26 and 2.73, respectively).

Late detection and associated factors among affected persons

The detection context was characterised by a predominantly passive approach (79.4% of cases were detected passively, compared with 20.6% detected actively), with 40.7% of cases involving a family

history and 26.7% involving treatment interruption. The median patient delay was 5 months. Late detection, i.e. grade 2 disability present at diagnosis, occurred in 33.7% of cases (59/175).

Late detection was strongly associated with a delay in seeking care. The median delay before the first consultation was 12 months for patients with G2D at diagnosis, compared with three months for those without. Furthermore, 45.9% of patients who waited over six months before consulting were diagnosed late, compared with 25.3% of those who sought care earlier ($P = 0.008$). In the bivariate analysis, sex was the only sociodemographic factor associated with late detection ($P = 0.032$); men had approximately twice the odds of women (OR: 2.01; 95% CI: 1.05–3.83). There was borderline evidence of an association with marital status ($P = 0.054$), whereas there was no association with age group, occupation, education or residence. Late detection was similarly frequent in Zou (32.6%) and Plateau (34.9%) ($P = 0.75$).

Two multivariable models were fitted. When adjusted for marital status alone, male sex remained an independent factor associated with late detection (aOR 2.08; 95% CI 1.01–4.28; $P = 0.046$). However, when leprosy-specific variables were added, the effect of sex attenuated and lost significance (aOR 1.76; 95% CI 0.80–3.83; $P = 0.157$). Instead, supernatural attribution of the disease emerged as the only independent factor (aOR 2.18; 95% CI 1.04–4.55; $P = 0.038$). Both models fitted the data adequately (Hosmer–Lemeshow $P = 0.30$ and $P = 0.89$), but their ability to discriminate was poor (AUC 0.63 and 0.69).

The sign that prompted consultation was strongly associated with G2D at diagnosis. After classification by the most advanced reported sign, 98 affected individuals (56.0%) sought treatment for an insensitive patch, 36 (20.6%) for sensory loss, 10 (5.7%) for visible G2D and 31 (17.7%) for another or unspecified sign. G2D at diagnosis occurred in 19.4%, 50.0%, 80.0% and 45.2% of these groups, respectively (see Table 6 and Fig. 2). Compared with presentation for an insensitive patch, presentation for sensory loss was associated with higher odds of G2D after adjusting for sex, supernatural attribution and detection mode (aOR 3.85; 95% CI 1.64–9.05). The estimate for presentation with visible disability (aOR 13.29; 95% CI 2.53–69.84) is included here for completeness, since presenting with this sign and experiencing this outcome describes the same clinical state. In this model, the adjusted odds ratio for male sex decreased to 1.65 (95% CI 0.79–3.49; $P = 0.19$), down from 2.01 (95% CI 1.05–3.83) in the bivariate analysis. The model's area under the curve (AUC) of 0.75 indicates apparent discrimination in this sample, but this was not externally validated.

Table 6
Late leprosy detection according to the sign that prompted consultation (n = 175).

Sign prompting consultation	n (%)	Late detection n (%)	Crude OR [95% CI]	Adjusted OR [95% CI]
Insensitive patch	98 (56.0)	19 (19.4)	1 (reference)	1 (reference)
Sensory loss	36 (20.6)	18 (50.0)	4.16 [1.83–9.47]	3.85 [1.64–9.05]
Grade 2 disability	10 (5.7)	8 (80.0)	16.63 [3.26–84.75]	13.29 [2.53–69.84]
Other or unspecified	31 (17.7)	14 (45.2)	3.42 [1.44–8.15]	3.56 [1.43–8.90]
Male sex (reference: female)	—	—	2.01 [1.05–3.83]	1.65 [0.79–3.49]
<i>Respondents reporting several signs are classified by the most advanced. Adjusted for sex, supernatural attribution of the disease and detection mode (active or passive); apparent AUC 0.75; Hosmer–Lemeshow P = 0.39. For the grade 2 disability category the presenting sign and the outcome describe the same clinical state; the odds ratio quantifies that overlap and is reported for completeness, not interpreted. Multiple-response frequencies before exclusive classification, among the 172 respondents to the module: insensitive patch 129 (75.0%), sensory loss 40 (23.3%), visible disability 10 (5.8%).</i>				

As a secondary comparison, we found no evidence of a difference in G2D prevalence between actively and passively detected cases (36.1% versus 33.1%; crude OR 1.14, 95% CI 0.53–2.46). This interval is consistent with both a halving and a 2.5-fold increase in the odds, so these data establish neither the equivalence nor the ineffectiveness of active case finding.

Discussion

Key findings

In a country that now notifies fewer than 100 cases of leprosy annually, the disease was more readily recognised by its perceived late consequences than by its initial manifestations. Only three in ten neighbourhood residents could identify an insensitive patch, whereas death was mentioned by the majority of people who were aware of the disease. Among affected individuals, the frequency of G2D increased steadily according to the stage at which the patient entered care: from one-fifth of individuals presenting with an insensitive patch, to four-fifths of individuals presenting with visible disability.

Recognition of early signs and community perceptions

Although leprosy is not in itself a fatal disease, death was the consequence most often cited (by 62.5% of aware residents), reflecting perceived severity rather than any clinical outcome. There is a discrepancy between the disease as these communities perceive it - grave and fatal - and the disease as it behaves, disabling but curable when treated early. This has consequences for detection. Someone who believes that leprosy is fatal and incurable has little reason to take a pale skin patch to a health centre.

Meanwhile, the impairment that does occur and that early treatment can prevent was identified by fewer than half of those familiar with the disease.

The residents interviewed were recruited from the same geographical area and included household members and unrelated neighbours. As the identity and diagnosis of the registered cases were never communicated during recruitment, the interviewees' answers reflect the knowledge circulating in the locality rather than that conveyed by contact tracing. However, they should not be taken as representative of the wider rural endemic population. Some residents shared a dwelling with an affected person, so the proportion who could name the early sign may be higher here than elsewhere. Knowledge was elicited through open questions, which measured spontaneous rather than prompted recognition. Those affected showed the reverse profile, which is consistent with knowledge acquired through experience. However, knowledge reported years after diagnosis may partly reflect education received during care.

Stage of entry into care

The gradient across presenting signs is programmatically informative, but it should not be interpreted as an independent causal effect. Visible disability as a presenting sign overlaps conceptually with G2D at diagnosis, which is why the corresponding odds ratio is reported but not interpreted. The sensory-loss group is more informative since it marks an intermediate stage at which progression can still be interrupted. Restricting the analysis to MB cases reduced clinical heterogeneity, but this limits the generalisability of the results to PB disease.

Grade 2 disability measures the extent of nerve damage at presentation rather than elapsed time. The convergent gradient with care-seeking delay supports its use here; the median delay was 12 months for late-detected cases compared with three months for the others. Since leprosy has a long and variable incubation period, commonly around five years and sometimes exceeding ten years, the interval between infection and the first visible sign is not part of what this indicator measures. This gradient is similar to the eight-month median delay associated with grade 2 disability in an Indian district [15], and is consistent with evidence from a systematic review identifying patient-side rather than health system delay as the dominant contributor in most endemic settings [16].

Two Beninese figures differ from ours. A national study of registered patients reported 58.3% with grade 2 disability and a median delay of 36 months from the first symptom to diagnosis [10], compared with our figures of 33.7% and 5 months, respectively. The former study recruited from leprosy treatment centres, which concentrate the most severe and protracted cases, whereas ours drew exhaustively from departmental registers. Our proportion is also lower than the 47–54% reported nationally between 2022 and 2025. This difference is expected because our register covers the period from 2013 to 2023. During this time, the national proportion increased from approximately one-quarter to approximately one-half, so an average of these figures falls between the two extremes. Restricting the analysis to MB cases has the opposite effect, since these carry a higher risk of disability. Therefore, the proportion observed here

is best interpreted as a conservative estimate of a phenomenon whose magnitude is determined by national surveillance rather than by these 175 patients.

Active and passive detection

This secondary comparison requires cautious interpretation: the detection mode was observed rather than assigned, and the active group comprised only 36 patients. Therefore, the absence of an observed difference does not demonstrate equivalence between the approaches. Active case-finding remains essential for locating patients who would otherwise be missed [17]. A cluster-randomised comparison of intensified contact screening with passive household screening in Bangladesh likewise found no lower proportion of G2D [18], whereas community-based interventions raising awareness of early signs in three Indian states were followed by a fall in G2D [19]. Our findings point in the same direction: the effect of case finding may be strengthened when communities and first-line workers can recognise a persistent patch with altered sensation. Education and active detection complement each other rather than compete.

Beliefs and attitudes

Beliefs point in the same direction. Supernatural attribution was more frequent among patients themselves (35.5%) than among residents (25.5%), and this association with late detection persisted after adjustment for the other factors considered (aOR 2.18). However, this association cannot be interpreted causally. As attribution was measured at the time of the interview, after the diagnosis had been made, it reflects how the illness had been understood, rather than what had delayed its detection. The fact that a quarter of residents attributed leprosy to witchcraft is similar to the 25.3% who attributed it to a spell in rural Cameroon [12]. By contrast, recognition of a microbial cause was much rarer here (3.4%), compared with the 19.7% reported in that setting. This difference may reflect the open-question format of our study as much as a genuine difference in knowledge. Causal beliefs and sign recognition belong to the same obstacle and can both be acted upon, unlike the sociodemographic profile of patients.

Attitudes diverged sharply between the two groups. More than three-quarters of residents refused to live with someone with leprosy, yet nearly nine in ten declared themselves willing to help detect cases. Treating the third who had not heard of leprosy as refusers would raise the apparent rate to 85.0%, without altering any association. This level is not exceptional; comparable attitudes have been documented in rural Cameroon, where fewer than half of respondents would shake hands with a patient, and in Nigeria. What is unusual is the coexistence of that refusal with near-universal willingness to be examined (95%) and to help find cases (88.6%) within the same respondents. Goodwill towards the control programme does not amount to tolerance of everyday proximity, and it is tolerance that determines whether someone will disclose an early symptom. Affected individuals showed the opposite pattern: more than three-quarters accepted cohabitation, as if experiencing the disease had dispelled the contagion-related fears that their neighbours retained. Therefore, willingness to contribute to control and acceptance of the person are two different things, and only the former is secured in these communities.

Sex differences

The male excess in late detection (aOR 2.08) was reduced once leprosy-specific variables and the presenting sign were considered (aOR 1.65; 95% CI 0.79–3.49). This suggests that men do not differ fundamentally, but rather present later in the same sequence. This coexists with lower use of traditional healers among men, suggesting that what delays them is postponement of care-seeking rather than an alternative therapeutic itinerary. This runs counter to reviews of early case detection, which identify women as the group whose diagnosis is delayed by restricted mobility, lower autonomy and concealment [20]. Nevertheless, male sex has been reported as a risk factor for disability elsewhere [21], and men were also in the majority in the national Beninese study [10]. Alternatively, women may be under-represented among registered cases in the first place, - itself a recognised form of delayed detection, - in which case our register-based sample would understate the delay experienced by women. Our data cannot separate the two. Among residents, however, male sex was associated with both better knowledge of early signs and less refusal of cohabitation. This double association is consistent with a link between information and tolerance and identifies women, who made up the majority of our resident sample, as a priority target for health education.

Acceptance of post-exposure prophylaxis

Where people cannot name the sign that should prompt them to visit a health centre, strategies that rely on self-presentation will continue to fall short. Nevertheless, 96.4% of residents would accept a medicine to avoid contracting leprosy. This included the third who had never heard of the disease, those unable to describe its initial symptoms and those who would not live next to a patient. Contact screening and post-exposure chemoprophylaxis, whose protective effect and programmatic feasibility are well-established [22–25], do not require the population to diagnose the disease, only to accept the offer of treatment.

The figure of 96.4% must be considered an upper bound since no medicine was actually offered, and stated willingness routinely exceeds observed uptake. Our robust acceptance rate was 73.9%, which lies between the 58.6% of Beninese contacts who agreed to take the medicine when asked before it was administered [11], and the 86.9% of screened contacts who took the medicine after tracing, education and screening in the LPEP programme [23]. Interpreted in this way, the three estimates are consistent.

The dissociation between the two levels of acceptance is a more instructive and robust result since it is internal to a single sample and instrument. Consent in principle was not influenced by knowledge. Acceptance that survived the constraints was higher among residents who could name the early sign (82.4% versus 70.1%; aOR 1.67), and the constraint responsible for this gap was tolerance of side effects rather than distance or time. A person who does not know what the medicine protects against has no reason to endure an unpleasant side effect. Knowledge does not create acceptance, which is already close to its maximum level. What knowledge does is determine whether acceptance remains once the offer incurs a cost. This was also demonstrated by the Beninese acceptability study at the point of administration, where poor knowledge was the strongest predictor of refusal [11]. Education is therefore

not an alternative to chemoprophylaxis, but rather a condition for its long-term success. Almost all of those who refused gave the reason that one does not take medicine for a disease one does not have, which suggests that the idea of prevention itself needs to be conveyed.

Generalisability

The estimates reported here relate to the Plateau and Zou departments and should not be applied elsewhere, but the mechanism they illustrate is not confined to these areas: it requires only that annual notifications have fallen sufficiently for the early form of the disease to have disappeared from collective memory, while the proportion of cases involving visible disability has not decreased in parallel. This combination may identify a recognisable class of settings approaching elimination, where the limiting factor could be what the population and first-line workers can recognise, rather than the number of people examined. This remains a plausible hypothesis, suggested by our findings rather than a conclusion established by them.

Implications for programmes

A programme that notifies fewer than a hundred cases a year, but finds half of them to be already disabled, faces a detection problem rather than a coverage problem. The findings support a focused communication strategy centred on persistent skin patches accompanied by definite loss or alteration of sensation, as well as numbness, tingling and early weakness. Images of advanced deformity may communicate severity, but they should not be the only visual representation of leprosy. First-line health workers also require periodic reinforcement. This need is documented in Benin, where four in five health workers surveyed nationally were unable to recognise the disease [10]. Low case numbers reduce clinical familiarity at a time when leprosy has largely disappeared from medical curricula [26]. Programmes should assess active case finding not only by the number of cases detected, but also by disability grade and diagnostic delay. Provider-initiated screening and post-exposure prophylaxis can complement recognition-based strategies, but stated willingness should not be equated with actual uptake. Clear counselling about prevention, eligibility and expected effects, such as urine discolouration, remains necessary.

Strengths and limitations

The main strengths of this study are the exhaustive register-based recruitment of MB cases in two departments; the linkage of a presenting sign derived from interviews to a disability grade recorded independently at diagnosis by programme nurses and confirmed by direct observation during the visit; and the comparison of recognition of early signs with citation of late consequences within the same respondents.

Several limitations qualify the findings. The cross-sectional design does not allow for causal inference. Affected individuals were identified in registers from 2013–2023 and interviewed at a later date. Of the 273 individuals identified, 98 could not be included, primarily because of death or migration. This loss most likely excluded the individuals with the most severe disabilities, so the observed proportion with

G2D is probably an underestimate. Recall extending up to eleven years, and varying substantially in duration between participants, may have attenuated or exaggerated the observed associations. Individuals who developed a disability may also have reconstructed their care-seeking history around the sign that ultimately prompted them to seek medical attention.

Neighbourhood residents were recruited within 100 m of registered cases, whose identity and diagnosis were never disclosed. The frame included individuals living with an affected person. Because the diagnosis was never disclosed, we treated these individuals as members of the general population of comparable rural endemic communities rather than as contacts defined by social distance. They are not representative of the national population. Nevertheless, residents of the same locality share health services and a sociocultural environment. The sample was widely dispersed and village-level clustering was limited. Applying the associated design effect left the conclusions unchanged; only the already marginal difference between departments became borderline.

Unlike the outcome, detection mode was reported by participants at interview rather than taken from the registers. Therefore, misclassification between active and passive detection cannot be excluded. It enters the analysis only as an adjustment variable and as a descriptive comparison. Since grade 2 disability is visible, interviewers could not be blinded to the outcome. However, the presenting sign was a factual item reported by the participant and coded from fixed response options, so differential misclassification is less plausible here than it would be for a subjectively assessed outcome. Several strata were small and the active-detection group was insufficient to establish equivalence with passive detection. All attitude and acceptance items were self-reported in a face-to-face interview, so social-desirability bias may have inflated favourable responses, particularly with regard to willingness to be examined and to accept preventive medication. Finally, stated willingness to accept preventive medication may exceed actual uptake under programme conditions.

Conclusions

In the rural endemic communities studied in southern Benin, leprosy was more commonly associated with the late consequences of the disease than with the initial insensitive patch. Presenting with sensory loss was associated with substantially higher odds of grade 2 disability (G2D) than presenting with a patch, identifying a clinically meaningful point for earlier action. Progress towards interrupting transmission should combine active case finding and contact-based prevention with communication about persistent patches with altered sensation, as well as reinforcing diagnostic skills among first-line workers. Where notifications have fallen without a corresponding fall in disability at diagnosis, the same question should be asked about the population's ability to recognise the disease. Prospective studies are needed to determine whether improving recognition shortens diagnostic delay.

Abbreviations

aOR

adjusted odds ratio

AUC

area under the receiver operating characteristic curve

CI

confidence interval

G2D

grade 2 disability

MB

multibacillary

ODK

Open Data Kit

OR

odds ratio

PNLLUB

Programme National de Lutte contre la Lèpre et l'Ulcère de Buruli (National Leprosy and Buruli Ulcer Control Programme)

SDDR-PEP

single double-dose rifampicin post-exposure prophylaxis

STROBE

Strengthening the Reporting of Observational Studies in Epidemiology

WHO

World Health Organization

Declarations

Ethics approval and consent to participate: The study protocol was approved by the National Ethics Committee for Health Research (Comité National d'Éthique pour la Recherche en Santé) of the Ministry of Health of Benin under reference CNERS 011/2024, session of 27 August 2024; the favourable opinion was signed and became effective on 15 October 2024, before any activity involving participants. The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants; the parent or guardian consented for minors, who also gave their own assent, and illiterate participants provided a fingerprint in the presence of an independent witness.

Consent for publication: Not applicable.

Availability of data and materials: The datasets generated and analysed during the current study are not publicly available owing to confidentiality and privacy considerations involving study participants, but are available from the corresponding author on reasonable request.

Competing interests: The authors declare that they have no competing interests.

Funding: The data used in this article are drawn from the research project “Étude de la faisabilité et de l’efficacité du dépistage et de la prise en charge intégrés des MTN-MC, associés à l’administration d’une double dose unique de rifampicine à titre de prophylaxie post-exposition chez des personnes exposées à la lèpre au Bénin et en Côte d’Ivoire (2PEP4LEP)”, funded by the ANESVAD Foundation and the Raoul Follereau Foundation under grant REG-3723/21. Representatives of both funders are co-authors and contributed to the design of the study and to the review of the manuscript; the funders had no role in data collection, in the statistical analysis or in the decision to submit for publication.

Authors’ contributions: Conception, design and data acquisition: RCJ, SDZ, ASYH, JGH, CJJ, AGM, PV. Writing, original draft: SDZ, FNCG. Data curation: SDZ, FNCG, JGH. Analysis and interpretation: SDZ, FNCG, RCJ, SGEA, VB, SIEA, KLMCS, CJJ, AGM, PV, AF, YTB. Review and editing: RCJ, SGEA, KLMCS, AT, CJJ, AGM, AF, ASYH, YTB. Funding acquisition: RCJ, AGM, CJJ, PV. All authors read and approved the final manuscript.

Acknowledgements: We thank all the members of the 2PEP4LEP project team and the Programme National de Lutte contre la Lèpre et l’Ulcère de Buruli in Benin for their administrative and technical support, and the Raoul Follereau and ANESVAD Foundations.

Clinical trial number: not applicable

References

1. World Health Organization. Global leprosy (Hansen disease) update, 2022: new paradigm — control to elimination. *Wkly. Epidemiol. Rec.* **98** (37), 409–430 (2023).
2. World Health Organization. Global leprosy (Hansen disease) update, 2023: elimination of leprosy disease is possible — time to act! *Wkly. Epidemiol. Rec.* **99** (37), 501–521 (2024).
3. World Health Organization. Global leprosy (Hansen disease) update, 2024: beyond zero cases — what elimination of leprosy really means. *Wkly. Epidemiol. Rec.* **100** (30), 365–384 (2025).
4. Programme National de Lutte contre la Lèpre et l’Ulcère de Buruli. *Rapports du monitoring annuel lèpre, 2022–2025* (Ministère de la Santé, Direction Nationale de la Santé Publique, 2025).
5. Gnimavo, R. S. et al. Trends of the leprosy control indicators in Benin from 2006 to 2018. *BMC Public. Health.* **20** (1), 1254. <https://doi.org/10.1186/s12889-020-09341-w> (2020).
6. World Health Organization. *Towards zero leprosy: global leprosy (Hansen’s disease) strategy 2021–2030* (World Health Organization, 2021).
7. World Health Organization Regional Office for South-East Asia. *Guidelines for the diagnosis, treatment and prevention of leprosy* (World Health Organization, 2018).
8. Freitas, L. R. S., Freitas, J. A. O., Penna, G. O. & Duarte, E. C. Evaluating machine learning models for predicting late leprosy diagnosis by physical disability grade in Brazil (2018–2022). *Trop. Med. Infect. Dis.* **10** (5), 131. <https://doi.org/10.3390/tropicalmed10050131> (2025).

9. Lockwood, D. N. J. Chronic aspects of leprosy-neglected but important. *Trans. R Soc. Trop. Med. Hyg.* **113** (12), 813–817. <https://doi.org/10.1093/trstmh/try131> (2019).
10. Gnimavo, R. S. et al. Associated factors study into the belated screening for leprosy in Benin. *PLoS Negl. Trop. Dis.* **16** (6), e0010533. <https://doi.org/10.1371/journal.pntd.0010533> (2022).
11. Djossou, P. et al. Acceptability and feasibility of chemoprophylaxis with single-dose rifampicin in four leprosy-endemic districts in Benin. *PLoS Negl. Trop. Dis.* **19** (4), e0013057. <https://doi.org/10.1371/journal.pntd.0013057> (2025).
12. Tabah, E. N. et al. Community knowledge, perceptions and attitudes regarding leprosy in rural Cameroon: the case of Ekondotiti and Mbonge health districts in the South-west Region. *PLoS Negl. Trop. Dis.* **12** (2), e0006233. <https://doi.org/10.1371/journal.pntd.0006233> (2018).
13. Murphy-Okpala, N. et al. Investigation of community knowledge, attitudes and stigma towards leprosy in Nigeria: a mixed-methods study. *Trans. R Soc. Trop. Med. Hyg.* **118** (10), 697–709. <https://doi.org/10.1093/trstmh/trae050> (2024).
14. von Elm, E. et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Lancet* **370** (9596), 1453–1457. [https://doi.org/10.1016/S0140-6736\(07\)61602-X](https://doi.org/10.1016/S0140-6736(07)61602-X) (2007).
15. Jalakam Venkata, S. P., Lotheti, S. & Bhimarasetty, D. M. Disabilities among newly reported leprosy cases in Visakhapatnam District, India: a cross-sectional study of prevalence and associated factors. *Cureus* **17** (6), e85207. <https://doi.org/10.7759/cureus.85207> (2025).
16. Dharmawan, Y., Fuady, A., Korfage, I. & Richardus, J. H. Individual and community factors determining delayed leprosy case detection: a systematic review. *PLoS Negl. Trop. Dis.* **15** (8), e0009651. <https://doi.org/10.1371/journal.pntd.0009651> (2021).
17. Mahato, R. K. et al. Evaluating active leprosy case identification methods in six districts of Nepal. *Infect. Dis. Poverty.* **12** (1), 111. <https://doi.org/10.1186/s40249-023-01153-5> (2023).
18. Naher, K. et al. Assessing the feasibility of an intensified extended contact survey (IECS) compared to passive household screening for leprosy in Bangladesh. *Trop. Med. Infect. Dis.* **10** (10), 274. <https://doi.org/10.3390/tropicalmed10100274> (2025).
19. Govindasamy, K. et al. A comparison of three types of targeted, community-based methods aimed at promoting early detection of new leprosy cases in rural parts of three endemic states in India. *PLoS One.* **16** (12), e0261219. <https://doi.org/10.1371/journal.pone.0261219> (2021).
20. Price, V. G. Factors preventing early case detection for women affected by leprosy: a review of the literature. *Glob Health Action.* **10** (sup2), 1360550. <https://doi.org/10.1080/16549716.2017.1360550> (2017).
21. Chen, X., Liu, H. B., Shui, T. J. & Zha, S. Risk factors for physical disability in patients with leprosy disease in Yunnan, China: evidence from a retrospective observational study. *PLoS Negl. Trop. Dis.* **15** (11), e0009923. <https://doi.org/10.1371/journal.pntd.0009923> (2021).
22. Moet, F. J., Pahan, D., Oskam, L., Richardus, J. H. & COLEP Study Group. Effectiveness of single dose rifampicin in preventing leprosy in close contacts of patients with newly diagnosed leprosy: cluster

- randomised controlled trial. *BMJ* **336** (7647), 761–764.
<https://doi.org/10.1136/bmj.39500.885752.BE> (2008).
23. Richardus, J. H. et al. Leprosy post-exposure prophylaxis with single-dose rifampicin (LPEP): an international feasibility programme. *Lancet Glob Health*. **9** (1), e81–90.
[https://doi.org/10.1016/S2214-109X\(20\)30396-X](https://doi.org/10.1016/S2214-109X(20)30396-X) (2021).
24. Schoenmakers, A., Mieras, L., Budiawan, T. & van Brakel, W. H. The state of affairs in post-exposure leprosy prevention: a descriptive meta-analysis on immuno- and chemo-prophylaxis. *Res. Rep. Trop. Med.* **11**, 97–117. <https://doi.org/10.2147/RRTM.S190300> (2020).
25. World Health Organization Regional Office for South-East Asia. *Leprosy/Hansen disease: contact tracing and post-exposure prophylaxis. Technical guidance* (World Health Organization, 2020).
26. Alemu Belachew, W. & Naafs, B. Position statement: LEPROSY: diagnosis, treatment and follow-up. *J. Eur. Acad. Dermatol. Venereol.* **33** (7), 1205–1213. <https://doi.org/10.1111/jdv.15569> (2019).

Figures

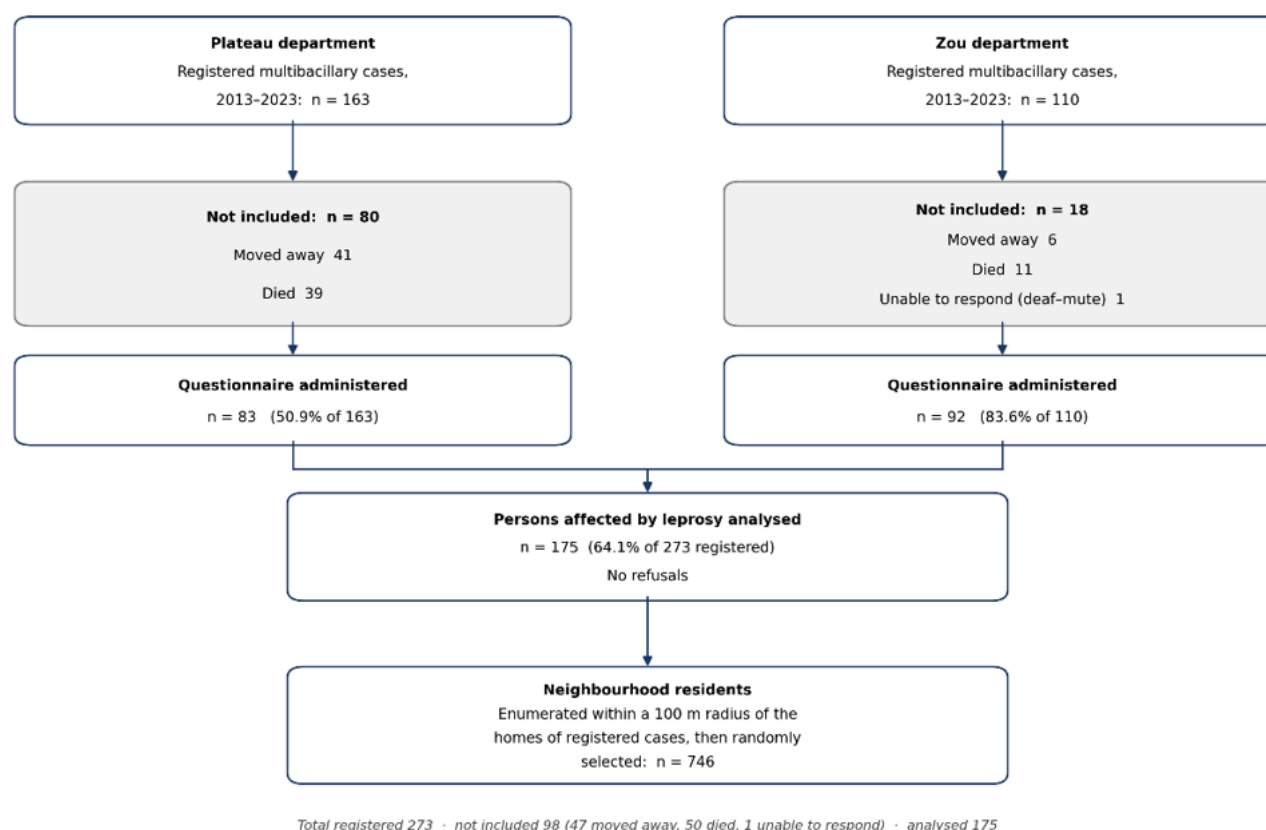


Figure 1

Participant flow diagram. Multibacillary cases registered by the national programme in Plateau and Zou over 2013–2023 (n = 273; 163 Plateau, 110 Zou), non-inclusions by department and reason (47 moved

away, 50 died, 1 unable to complete the interview), affected persons to whom the questionnaire was administered (n = 175; 83 Plateau, 92 Zou; participation rate 64.1%), and neighbourhood residents enumerated and randomly selected within a 100 m radius of their homes (n = 746; 403 Plateau, 343 Zou).

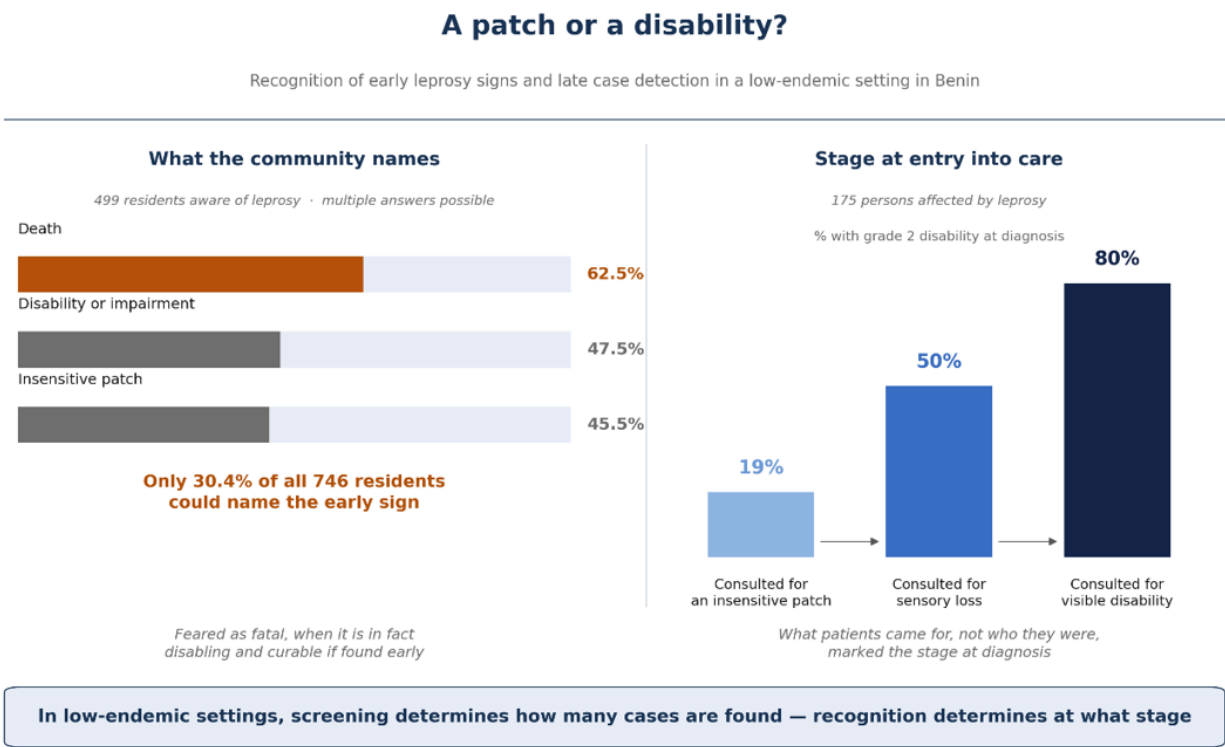


Figure 2

Grade 2 disability at diagnosis according to the sign that prompted consultation (n = 175). Proportion of affected persons with grade 2 disability recorded at diagnosis among those presenting with an insensitive patch (19.4%; 19/98), sensory loss (50.0%; 18/36), visible disability (80.0%; 8/10) and another or unspecified sign (45.2%; 14/31). Respondents reporting several signs are classified by the most advanced sign.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryInformation.docx](#)