Routine health information system and health facility data for neglected tropical diseases

Buruli ulcer

World Health Organization

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Contents

Acknowledgements . . . iv

Abbreviations . . . v

1. Introduction . . . 1
1.1 Approach to development of this guidance . . . 2
1.2 Declarations of interest . . . 2
1.3 Scope of this document . . . 2
1.4 Objectives . . . 2
1.5 Target audience . . . 3

2. About Buruli ulcer data . . . 4
2.1 Key features . . . 4
2.2 Data collection and reporting . . . 4
2.3 WHO-recommended case definitions . . . 4
2.4 Other WHO-recommended definitions with implications for clinical case management . . . 4

3. Data quality . . . 6
3.1 Timeliness of data . . . 6
3.2 Completeness of data . . . 6
3.3 Internal consistency of reported data . . . 6

4. Core indicators . . . 7

5. Core analyses . . . 9
5.1 Epidemiological analysis . . . 11
5.2 Indicators for reporting clinical examination observations . . . 12
5.3 Diagnosis . . . 14
5.4 Treatment data . . . 15
5.5 Tracking treatment outcomes . . . 16

References . . . 18

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Abbreviations

BU	Buruli ulcer
NTD	neglected tropical disease
PCR	polymerase chain reaction
WHO	World Health Organization

1. Introduction

Buruli ulcer (BU) is a skin-related neglected tropical disease (skin NTD) caused by infection with *Mycobacterium ulcerans*. BU is the third most common mycobacterial disease after tuberculosis and leprosy in people who are not immunocompromised. The infection manifests in non-ulcerative forms as nodules, plaques and/or oedemas, which ulcerate within 4–6 weeks and display characteristic undermined edges and yellowish-white necrotic slough *(1)*. Most lesions occur on the lower limbs.

BU has been reported from 33 countries worldwide. The main foci are in West and Central Africa and in Australia (Victoria state), where the disease is highly concentrated in small geographical areas. The number of cases varies seasonally in some countries, whereas in others there is no seasonal trend. The increase in cases has been associated with heavy periods of rainfall and changes in the environment. In the World Health Organization (WHO) African Region, fragmentation and destruction of the landscape have been suggested as risk factors. The niche, ecology and transmission of the environmental human pathogen *M. ulcerans* are poorly understood. As a result, active epidemiological surveillance is important to control the disease, and drivers of its local occurrence should be closely investigated. In areas of Africa endemic for BU, the prevalence of HIV is high, with rates of 1–5% in adults. However, there is limited information on the prevalence of BU–HIV coinfection *(2)*.

The mode of transmission of BU is not known. In the absence of a clear understanding of how transmission occurs and a vaccine against the disease, the main control strategy focuses on early case detection and comprehensive treatment of individual patients to avoid complications and sequelae. As the exact transmission route remains unknown, no clear recommendations can be given on prevention, but BCG vaccine appears to offer some limited protection.

Diagnosis is based on characteristic clinical and epidemiological features, with laboratory-confirmation using histopathology, culture and polymerase chain reaction (PCR) *(3)*. During the past two decades, treatment of BU has shifted from mainly surgery to an 8-week course of antibiotics (rifampicin and clarithromycin) *(4)*.

In 1998, participants at a conference on BU control and research (Yamoussoukro, 6–8 July 1998) expressed concern about the increasing burden of cases, particularly in West Africa, and recognized the importance of early case detection and treatment. Signatories to the *Yamoussoukro declaration on Buruli ulcer (5)* called upon policy-makers to take action to support control of the disease, pledged to collaborate in research on its transmission and prevention, and affirmed their determination to intensify action against the disease.

In 2009, Heads of States of countries affected by BU participated in a second high-level meeting in Benin (Cotonou, 30 March 2009) and adopted the *Cotonou declaration on Buruli ulcer (6)*, calling for greater political commitment for BU control through early detection, wider access to antibiotic treatment and support for research.

In 2013, a WHO meeting on BU control and research (Geneva, 25–27 March 2013) defined four programmatic targets to be met by endemic countries by the end of 2014 *(7)*. These targets included laboratory (PCR) confirmation of *M. ulcerans* infection; lesion category and ulceration at diagnosis as proxies for disease progression or severity (as a result of late reporting); and functional limitation (reflecting sequelae of severe and advanced disease and resulting in disability).

In 2022, 11 countries reported 2121 suspected and clinically diagnosed cases to WHO. Of the 982 (46.3%) laboratory-confirmed cases, 40.7% completed a full course of antibiotic treatment and 25.2% were classified as category III (late stage) at diagnosis. In 2021, 12 countries reported 1665 cases. Of the 851 (51.1%) laboratory-confirmed cases, 43% completed a full course of antibiotic treatment and 25.5% were classified as category III at diagnosis.

As of 2023, integrated surveillance, active case-finding and capacity strengthening of health workers has been increasing in all the countries and territories classified by WHO as endemic. *Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030* ("the road map") *(8)* sets disease-specific targets, sub-targets and milestones for BU control. One of the ultimate targets is to achieve < 10% proportion of cases in category III (late stage) at diagnosis by 2030.

1.1 Approach to development of this guidance

This guidance was developed based on a template provided to health programmes by the WHO Division of Data, Analytics and Delivery for Impact. WHO regional advisers and disease focal points in the WHO Global Neglected Tropical Diseases Programme provided technical content in alignment with the road map. A drafting team comprising WHO technical officers and BU disease experts working on skin NTDs at global, regional and country levels contributed to the writing and review of initial drafts of the document. Independent BU experts and selected national programme managers from BU-endemic countries reviewed the guidance for technical accuracy and relevance.

1.2 Declarations of interest

Contributing disease experts external to WHO submitted signed disclosures of declarations of competing interests, academic or scientific activities, which were reviewed. No conflicts of interest were identified.

1.3 Scope of this document

This document addresses the collection, aggregation and basic summary analysis of individual data on BU cases collected at BU treatment centres based on the BU 01 and BU 02 forms. All of the updated forms are available in Word and PDF formats on the WHO website *(9)*.

Data not specifically addressed in this document are those related to:

- community-based active case search activities; and
- individual BU patient file number and case management notes.

1.4 Objectives

This document provides guidance on the analysis and use of routine BU data collected at the health facility level. It presents core facility indicators and analysis, provides suggestions for questions on review of data quality as well as considerations and limitations for using the data and analysis. By the end of this document, readers should be able to:

- describe core BU indicators and notable trends in incidence, geographical distribution and progress towards control of the disease;
- monitor clinical case management outcomes;
- understand how to interpret changes in trends over time, by gender, age group and location; and
- assess data quality and understand its implications when interpreting data.

1.5 Target audience

This document is relevant for different members of the health workforce working on BU control, including:

- health workers at health facilities diagnosing and treating BU cases;
- data clerks at health facilities managing entries into the routine health information system;
- data managers and data analysists working with the national routine health information system at district and higher levels;
- ministry of health decision-makers and epidemiologists working in the national BU programmes, and health information system managers at district and higher levels;
- technical staff of partner organizations supporting the strengthening of national BU programmes, the diagnosis and case management of BU cases in health facilities or health systems; and
- consultants and staff working at research institutes involved with the assessment and improvement of BU control activities and specifically with the analysis of BU data.

2. About Buruli ulcer data

2.1 Key features

Clinical indicators monitor aggregated data on:

- presentation at clinical examination in order to track timing of access to treatment and improve early detection of cases;
- laboratory PCR tests in order to indicate access to diagnosis and capacity to confirm cases;
- antibiotics in order to monitor access to treatment and successful completion of treatment regimens;
- core morbidity and mortality for all health facilities in endemic countries; and
- given the focal nature of the disease, more detailed indicators for BU treatment centres in endemic areas.

2.2 Data collection and reporting

Data from BU programmes are collected using basic data collection forms: BU 01 and BU 02 *(9)*. Data from health facilities are aggregated on a health facility reporting form for onward reporting to the national level.

2.3 WHO-recommended case definitions

2.3.1 Suspected case

Any person with painless nodule, papule, plaque or oedema evolving into a painless ulcer with undermined edges, often leading to invalidating sequelae in an endemic area.

2.3.2 Confirmed case

A suspected BU case confirmed by direct microscopy, histopathology, culture, mycolactone test or PCR. Currently, PCR is the main test used (the other tests can be used but have lower sensitivity).

2.4 Other WHO-recommended definitions with implications for clinical case management

2.4.1 Type of case

- New BU case: a person presenting with a BU ulcer lesion who has not previously received a complete course of antibiotic treatment for the disease.
- Recurrent BU case: a patient who has previously received a complete course of antibiotic treatment for BU and who presents with a lesion at another site or lesions at the same site within 1 year of the end of the last antibiotic treatment.

2.4.2 Joint limitation at initial clinical examination

A patient who is unable to move an affected joint over the normal range of movement at the time of clinical diagnosis.

2.4.3 Category of case at initial clinical examination

- Category I: a BU case who presents with a single lesion ≤ 5 cm in diameter
- Category II: a BU case who presents with a single lesion 5–15 cm in diameter
- Category III: a BU case who presents with a single lesion > 15 cm in diameter, with multiple lesions, lesions at critical sites or osteomyelitis.

3. Data quality

One of the challenges of interpreting health facility data is that responsibility for data recording, entry, cleaning and management is distributed across many individuals and programme entities. Unlike special studies or surveys, resources for entering and cleaning data are often limited in health facilities, impacting the quality and usability of routine monitoring data. Systems and protocols must therefore be established to enhance good data collection and reporting to facilitate data analysis and use. However, as for all data sources, any analysis must consider whether the results are affected by data quality issues.

The WHO data quality review (DQR) toolkit provides guidance for defining measures of data quality, conducting a desk review to assess data quality, and conducting data verification of routine facility data systems *(10, 11)*. The domains used most frequently for periodic assessments of BU ulcer data are summarized below.

3.1 Timeliness of data

Data timeliness refers to whether reporting units submit their data according to the timeline set by national health information management system guidelines.

3.2 Completeness of data

Data completeness measures the extent to which priority data elements are included in each report. Both timeliness and completeness of reporting can be assessed at national level and at any subnational level (e.g. facility, district, regional). Both timeliness and completeness can also be assessed separately for specific data forms used in reporting. For example, the collection of BU samples and completion of the laboratory request form, the time between collection and transfer to the reference laboratory for PCR and vice-versa, the time it takes for the health facility to receive the results can assessed both in timeliness and completeness. Delays on either side can lead to postponement of antibiotic treatment.

3.3 Internal consistency of reported data

The internal consistency of reported data takes multiple forms: from identifying outliers (i.e. reported values which are unusually high or low compared with those of other reporting units or compared with historical performance). Indicators which are related to each other can also be used to develop internal consistency checks (e.g. if a country is reporting a high number of BU cases in adults in Africa, such as 80% compared with the normal figure of about 50%), automatically, something is wrong with the clinical diagnosis. In the same way, if more than 80% of cases lesions are on the lower limb instead of 60%, then there is a problem with the clinical diagnosis. This is the reason why it is important that health workers diagnosing and treating BU cases should carefully consider the history, clinical and epidemiological factors in making the diagnosis.

4. Core indicators

The recommended minimum core indicators, definitions, disaggregation and data sources for BU monitoring and surveillance are provided in Table 1. Obtaining data from individual BU case registers as the first primary data collection point is the method preferred over aggregate forms to ensure high data quality.

Table 1. Buruli ulcer core indicators for monitoring and surveillance

Core indicators	Definition	Disaggregation	Comments
Epidemiology			
Number of suspected BU cases	Number of suspected BU cases	• By type of patient (new/recurrent) • By age group (years) (< 5, 5–14, ≥ 15) • By sex • By administrative unit(s)	• Number of BU cases is part of the core morbidity data. • This indicator is part of the SDG indicators for NTDs.
Number of confirmed BU cases	Number of laboratory PCR confirmed BU cases	• By type of patient (new/recurrent) • By age group (years) (< 5, 5–14, ≥ 15) • By sex • By administrative unit(s)	• Number of BU cases is part of the core morbidity data.
Confirmed BU incidence	Number of new PCR confirmed BU cases per 10 000 population = Number of new BU cases / population of administrative area × 10 000	• At lowest administrative level available	• Based on the number of new BU cases reported. • Population data at finest administrative level are required.
Number of endemic villages	Number of endemic villages, where at least 1 new confirmed BU case has been reported within the past 3 years	• At finest administrative level available	• Based on the number of new BU cases reported.
Population at district level at risk of BU	Population at risk at district level where at least 1 new confirmed BU case has been reported during the past 3 years	• At district level	• Based on the number of new autochthonous BU cases reported. • Population data at finest administrative level are required.
Proportion of cases detected by type of referral	% of PCR confirmed BU cases by each referral type = Number of cases detected by referral type / Total number of PCR confirmed BU cases × 100	• By type of referral (self-referral, third party, other) • At finest administrative level available	

Core indicators	Definition	Disaggregation	Comments
Clinical examination			
Proportion of PCR confirmed cases with joint limitation	% of joint limitation among PCR BU confirmed cases = number of PCR confirmed BU cases presenting joint limitation / total number of PCR confirmed BU cases × 100	• From lowest administrative level to district level	• Data from BU register (BU 02) • Indicative of late detection • WHO recommends that less than 15% of the BU cases should present with joint limitation
Proportion of PCR confirmed Category III BU cases	% of PCR confirmed BU category III cases = number of PCR confirmed BU category III cases / total number of PCR confirmed BU cases × 100	• From lowest administrative to district level	• Data from BU register (BU 02) • Indicative of late detection • WHO recommends that less than 25% of the BU cases should present in category III.
Proportion of HIV+ PCR confirmed BU cases	'% of HIV+ among PCR confirmed BU cases = number of HIV+ cases among PCR confirmed BU cases / total number of PCR confirmed BU cases × 100	• From lowest administrative level to district level	
Individual treatment outcomes			
Proportion of antibiotic treatment completed of PCR confirmed BU cases	% of antibiotic treatment completed* = Number of new PCR confirmed BU cases that have completed their antibiotic treatment / Total number of new PCR confirmed BU cases treated x 100 ** Antibiotic treatment completed: 56 doses completed within a period of 70 days (flexible approach). If a patient misses 7 days/doses or less (continuously or intermittently), this is considered antibiotic treatment completed. But all patients should be encouraged to complete the 56 days of treatment continuously.*	• From lowest administrative level to district level	• Data from BU register (BU 01)
Proportion of PCR confirmed BU cases receiving surgery	% of PCR confirmed BU cases treated by surgery = Number of PCR confirmed BU cases treated by surgery / Total number of PCR confirmed cases × 100	• From lowest administrative level to district level	
Proportion of healed PCR confirmed BU cases	% of healed PCR confirmed BU cases = Number of healed PCR confirmed BU cases / Total number of PCR confirmed BU cases × 100	• From lowest administrative level to district level	
Proportion of PCR confirmed BU cases lost to follow up	% of PCR confirmed BU cases lost to follow up = Number of PCR confirmed BU cases lost to follow up* / Total number of PCR confirmed BU cases × 100 ** Lost to follow up = patient disappears after starting treatment and is not recovered.*	• From lowest administrative level to district level	

BU: Buruli ulcer; NTD: neglected tropical disease; PCR: polymerase chain reaction; SDG: Sustainable Development Goal.

5. Core analyses

This section summarizes each of the recommended core data quality analyses and the factors to consider in their interpretation.

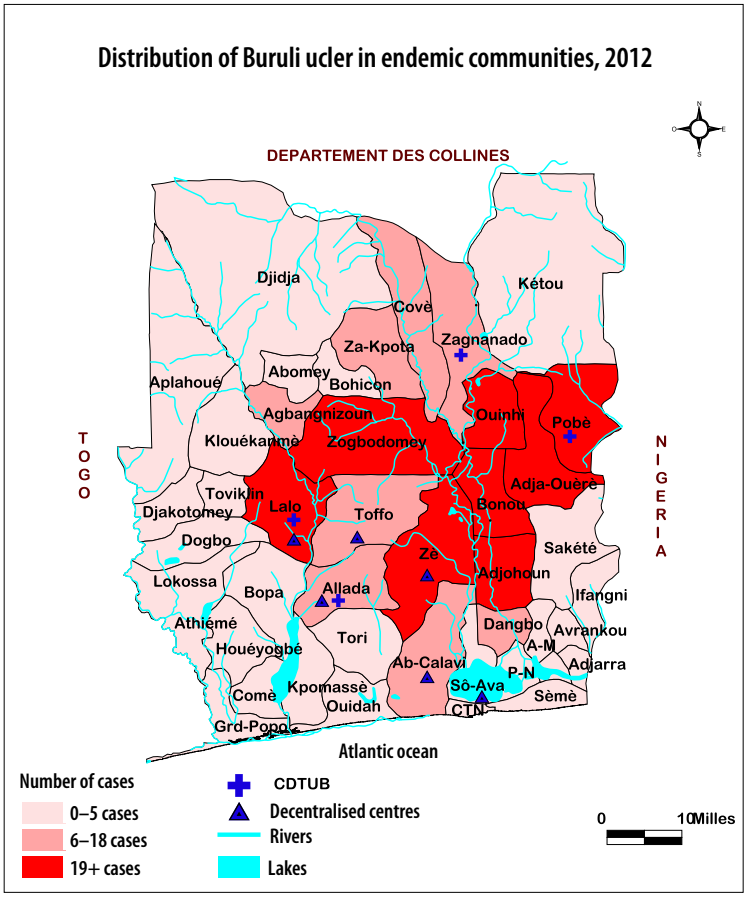
The purposes of the core analyses are:

- to assess the suitability of the data in guiding analysis of BU programme indicators;
- to identify the weaknesses in data quality, including accuracy, completeness, timeliness and consistency; and
- to identify health facilities with data quality issues and challenges in implementing BU programme interventions.

The four types of analysis are:

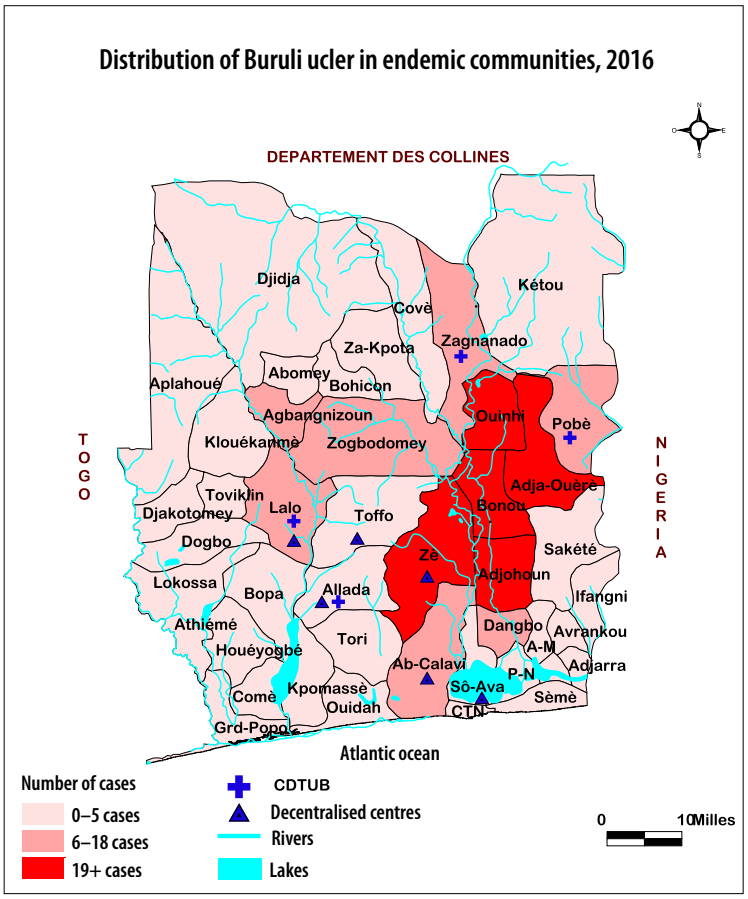
- geographical location of cases (Fig. 1);
- time series trends, by month, by year (Fig. 2);
- data disaggregation by gender, age-group, geographical location and BU wound category; and
- clinical treatment outcomes.

Fig. 1. Geolocation of cases



Data source: National Leprosy and Buruli Ulcer Control Programme, Benin.

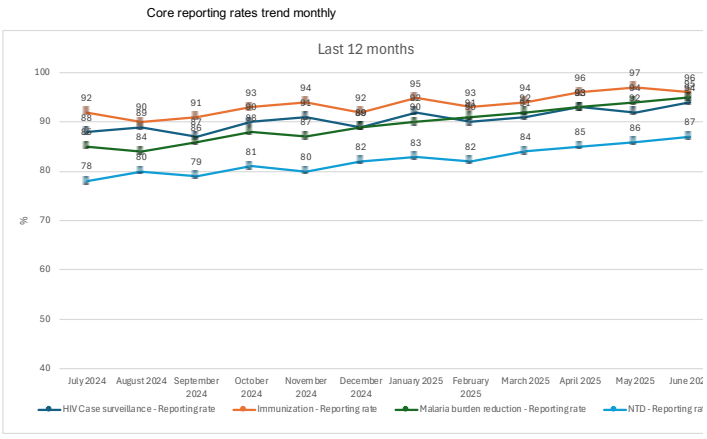
Fig. 1. *continued*



Data source: National Leprosy and Buruli Ulcer Control Programme, Benin.

Fig. 2. Time series trends, by month and by year

	Last 3 months			
	HMIS Reporting rate	ANC Reporting rate	NTD Reporting rate	NTD_1 Reporting rate
National / Region A / District A-1	30	33.3	30	30
National / Region A / District A-2	28	0	28	29
National / Region A / District A-3	33.3	0	33.3	31.5
National / Region A / District A-4	33.3	0	33.3	33.3
National / Region A / District A-5	23.8	3	23.8	30
National / Region A / District A-6	33.3	31.4	33.3	31.5
National / Region A / District A-7	31.9	1.5	31.9	31.9
National / Region B / District B-1	23	17.9	23	28.7
National / Region B / District B-2	33.3	1.7	33.3	33.3
National / Region B / District B-3	27.3	0	27.3	33.3
National / Region B / District B-4	33.3	30.2	33.3	33.3



Data source: Ministry of Health data. In: WHO Integrated Data Platform *(12)*.

5.1 Epidemiological analysis

Before interpreting trends in the epidemiological data, any data quality issues should be investigated *(10, 11)*. If you see any sudden changes in trends, first check the data to make sure there has not been any error in data entry.

5.1.1 Purpose

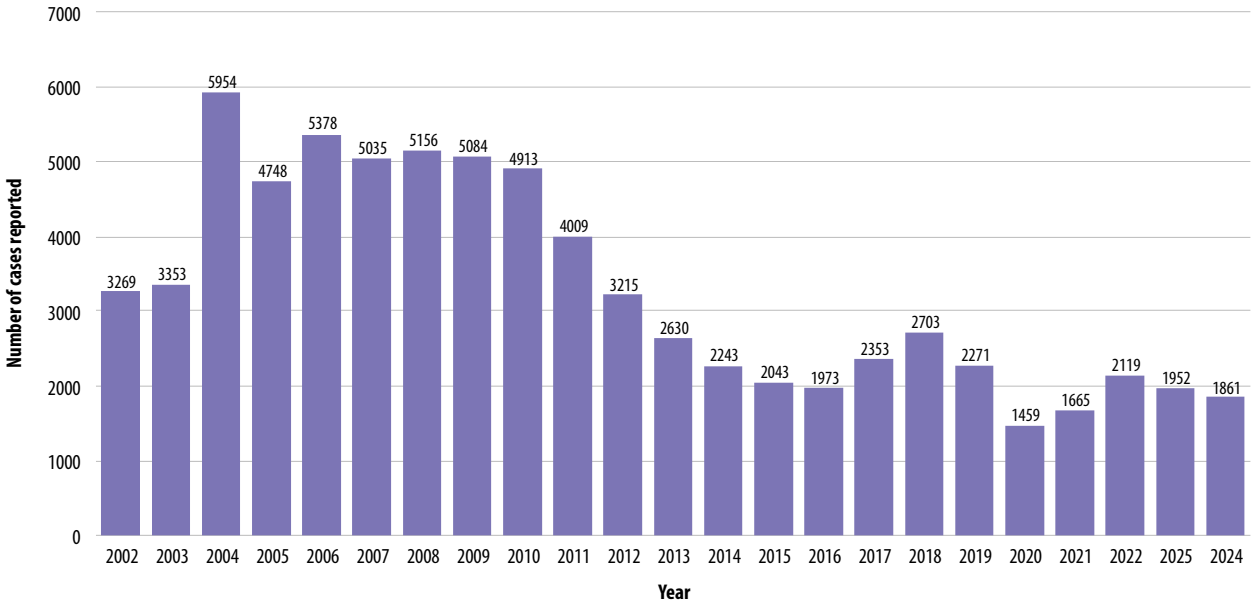
The purpose of the epidemiological analysis is:

- to monitor trends in disease incidence;
- to monitor geographical location of cases;
- to assess progress towards control of the disease;
- to track the geographical distribution of cases in relation to the location of BU treatment centres; and
- to monitor case-load at each major treatment facility.

5.1.2 Type

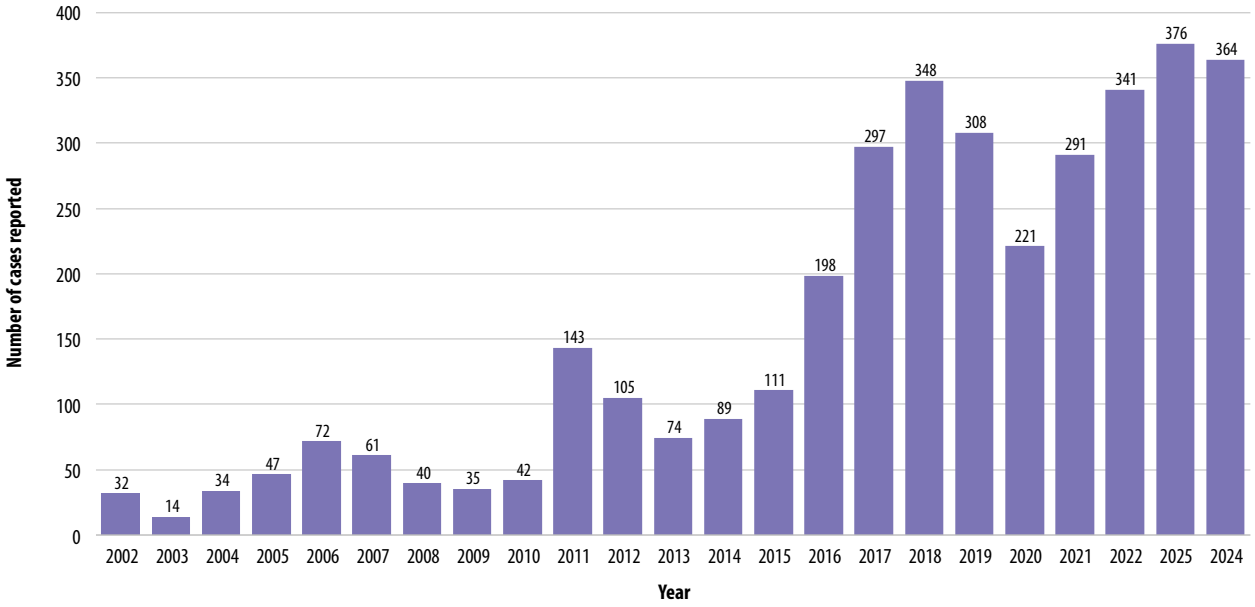
The type of analysis is time series by: (a) Number of cases by year (b) Number of cases globally and by WHO region and country (see examples in Fig. 3 and Fig. 4).

Fig. 3. Number of BU cases reported globally, 2002–2020



Data source: Ministry of Health data. In: WHO Global Health Observatory *(13)*.

Fig. 4. Number of BU cases reported by country (Australia), 1991–2021



Data source: WHO Global Health Observatory *(13)*.

5.1.3 Interpretation

Charts and maps depict the pattern of prevalence in several districts. It is important to consider the efficiency of the existing surveillance system, especially community activities such as outreach and active case-finding, and the capacity of the health system to confirm and report cases.

5.2 Indicators for reporting clinical examination observations

Buruli ulcer often starts as a painless swelling (nodule), a large painless area of induration (plaque) or a diffuse painless swelling of the legs, arms or face (oedema). The disease may progress with no pain and fever. Without treatment, or sometimes during antibiotic treatment, the nodule, plaque or oedema will ulcerate within 4 weeks. Bone is occasionally affected, causing deformities. Lesions are frequent in the limbs: 35% on the upper limbs, 55% on the lower limbs and 10% on other parts of the body. Health workers should be careful when diagnosing the disease in patients with lower leg lesions to avoid confusion with other causes of ulceration such as diabetes, arterial and venous insufficiency lesions.

The disease is classified into three categories of severity:

- category I single small lesion (32%);
- category II non-ulcerative and ulcerative plaque forms (35%); and
- category III disseminated and mixed forms such as osteitis, osteomyelitis and joint involvement (33%).

The objective of BU control is to minimize suffering, disabilities and socioeconomic burden. Early detection and antibiotic treatment are the cornerstones of the control strategy. The core clinical indicators used to measure progress in BU control are:

- the proportion of cases in category III (late stage) at diagnosis;
- the proportion of laboratory-confirmed cases; and
- the proportion of confirmed cases who have completed a full course of antibiotic treatment.

Additional indicators may be used to track criteria for referral to level 2 and 3 health care facilities. These include:

- all ulcers > 2 cm;
- all oedematous and plaque forms;
- lesions involving deeper structures including bone;
- lesions on the head and neck, genitalia, breast and fingers;
- difficult diagnoses (clinically and by laboratory methods); and
- systemically unwell patients.

5.2.1 Rationale for clinical indicators

Category III lesions are indicators of late detection. WHO recommends that the proportion of category III lesions should be less than 10% at diagnosis time by 2030.

The indicator for ulcerative lesions should be interpreted with caution as it is strongly influenced by patient immunity. Indeed, patients with high immunity may not present big lesions several weeks or months after infection. Conversely, patients with low immunity may develop extensive lesions within a few days.

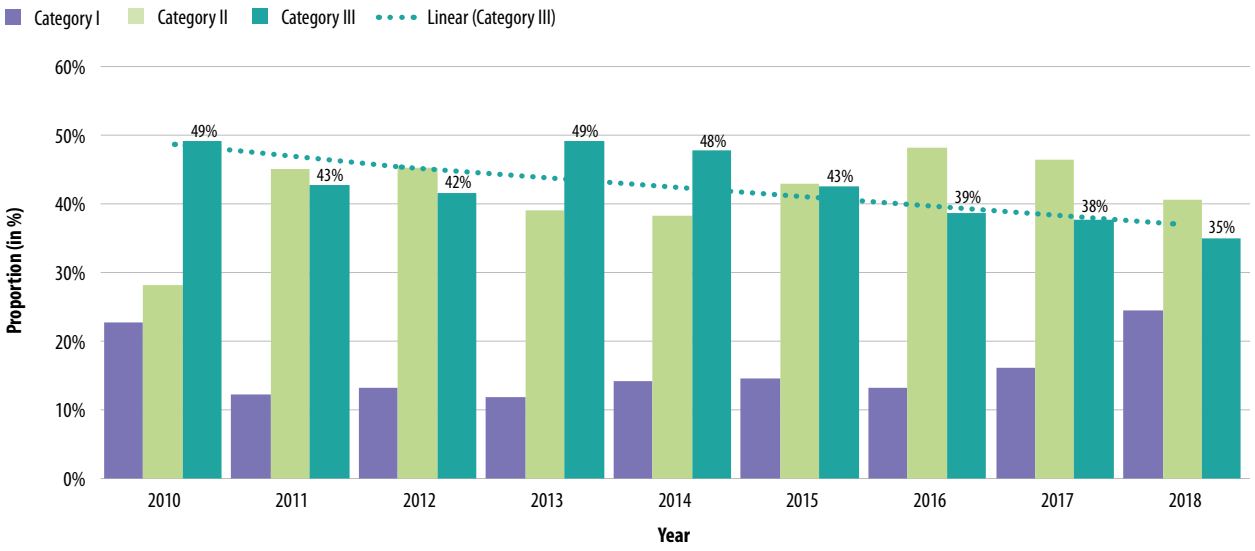
5.2.2 Analysis

The types of analysis are:

- category of lesions by gender and by age-group; and
- category of lesions, over time.

Fig. 5 provides an example of the proportion of category III lesions over time, depicting a decrease from 49.1% in 2010 to 34.9% in 2018 and showing progress over the years in early diagnosis.

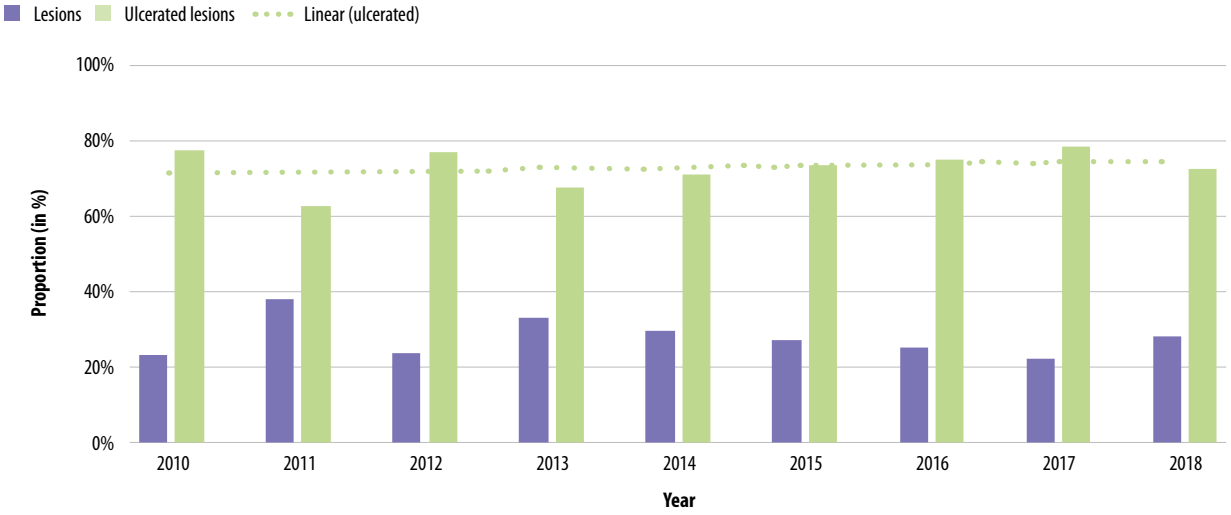
Fig. 5. Category III lesions, 2010–2018



Data source: National Leprosy and Buruli Ulcer Control Programme, Benin.

Fig. 6 shows an example of category II lesions over time, depicting a linear increase.

Fig. 6. Category II lesions, 2010–2018



Data source: National Leprosy and Buruli Ulcer Control Programme, Benin.

5.2.3 Interpretation

Ulcerated lesions are indicators of late detection. WHO recommends that the proportion of ulcerated lesions at diagnosis should be less than 60%. The proportion of ulcerated lesions varied between 60% and 78% from 2010 to 2018 (see also Fig. 6).

5.3 Diagnosis

This section summarizes each of the core analyses that are recommended for the diagnosis of BU and the factors to be taken into consideration in their interpretation.

5.3.1 Purpose

The purpose of the core analysis is to monitor access to, type and performance of BU diagnosis.

Four standard laboratory methods can be used to confirm BU: *IS2404* PCR, direct microscopy, histopathology and culture. The turnaround time of a PCR test is 3–7 days. Better and simpler diagnostics are desirable to enable early confirmation of diagnosis and facilitate timely management of the disease.

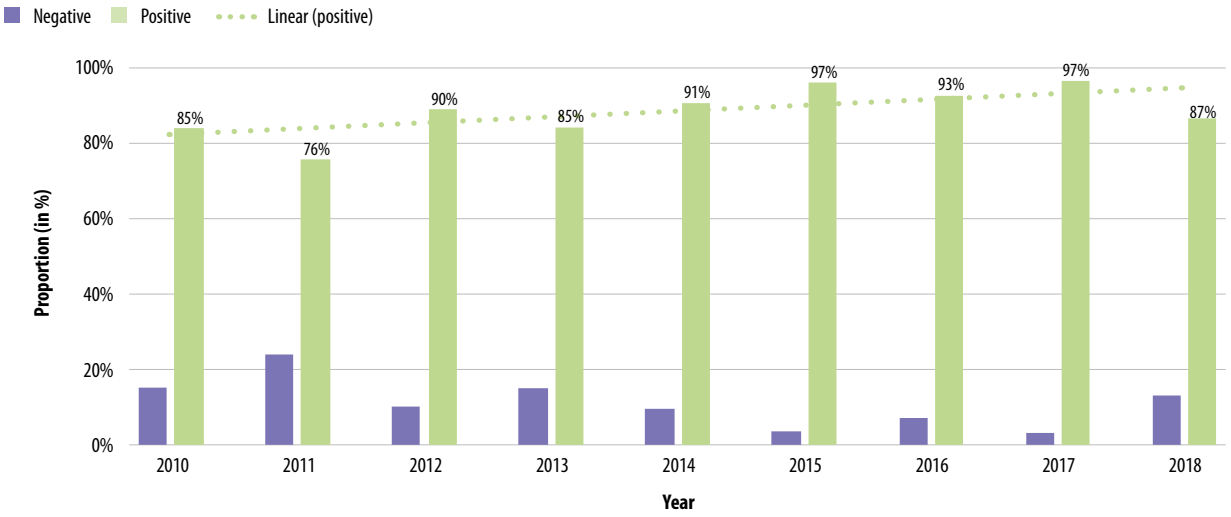
5.3.2 Analysis

The analysis is of laboratory PCR-confirmed cases, over time by gender and by age-group.

5.3.3 Interpretation

PCR for *IS2404* is the reference standard for confirmation of BU. WHO recommends that at least 95% of suspected cases should be confirmed by PCR by 2030. The proportion of PCR-confirmed cases presented in Fig. 7 varies between 76% and 97%; this is a good performance.

Fig. 7. PCR-confirmed cases, 2010–2018



Data source: National Leprosy and Buruli Ulcer Control Programme, Benin.

Laboratory PCR confirmation is influenced by the ability of health workers to identify suspected cases, collect appropriate samples and transport them to the laboratory. It is important that health workers are properly trained in sample collection and that laboratories organize periodic internal and external quality controls.

5.4 Treatment data

5.4.1 Purpose

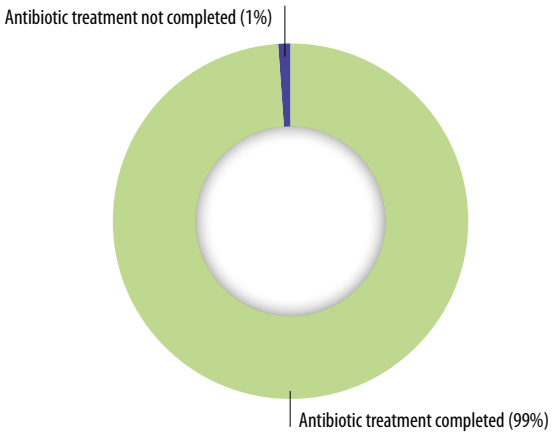
The purpose of the analysis is to monitor:

- access to treatment, by sex, by age group; and
- completion of treatment, by sex and by ag group.

5.4.2 Analysis

The completion rate is highly influenced by the accessibility to treatment and the availability of antibiotics at health facilities. It is important to monitor completion of treatment to reduce antibiotic resistance. WHO recommends that, by 2030, at least 98% of confirmed cases should complete a full course of antibiotic treatment. Further analysis of the data by gender and age-group can identify the characteristics of individuals not completing treatment, so that appropriate remedial approaches can be implemented to increase treatment completion rates in the context of the affected population (Fig. 8).

Fig. 8. Completion of treatment



Data source: Buruli ulcer detection and treatment centre, Lalo, Benin, 2019.

5.5 Tracking treatment outcomes

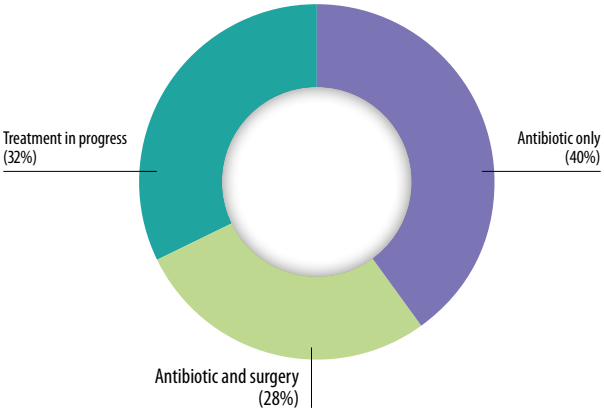
5.5.1 Purpose

The purpose of tracking treatment outcomes is to monitor:

- the initial and longer-term effectiveness of treatment (recurrence);
- the presence of disability at the time of the healing; and
- patients who are cured without surgery.

The example in Fig. 9 shows that one in three patients received surgery and 40% healed with antibiotic treatment alone.

Fig. 9. Monitoring of patients who are cured without surgery



Data source: Buruli ulcer detection and treatment centre, Lalo, Benin, 2019.

These indicators are strongly influenced by the precocity of the diagnosis, the availability of surgical services and the attitude of health workers towards surgery decision-making. Indeed, small lesions (category I and II) generally heal without surgery. Health workers are therefore encouraged to delay the decision to operate, especially for patients with lesions in critical areas such as the face and genital areas.

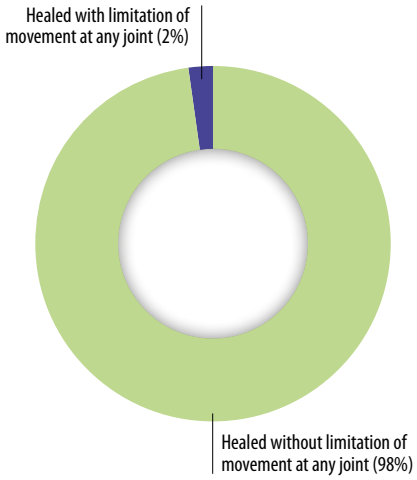
A functional limitation score should be applied to describe the scope of joint movement, such as:

1. Moves easily normally: the patient can perform the limb movement without difficulty and at a level comparable with that of other community members of the same sex and age.
2. Moves with difficulty: the patient can perform the limb movement but the level of performance is not the same as before BU, the level is not comparable with that of other community members of the same sex and age, or the activity could be performed at the same level but only with difficulty.
3. Unable to move at all: the patient cannot perform the limb movement without help from others because of BU, both if physically impossible and if not possible because the patient for example is avoiding the activity since he or she is afraid to damage the scar tissue.

5.5.2 Analysis

It is important to show the outcome of the intervention at the end of the patient's care. The presence of disability at the time of healing is indicative of gaps in early diagnosis and in quality of patient care including wound care, pain management and prevention of disabilities (Fig. 10).

Fig. 10. Monitoring disability at the time of healing



Data source: Buruli ulcer detection and treatment centre, Lalo, Benin, 2019.

5.5.3 Interpretation

It is important to show the outcome of clinical treatment at the end of the patient's care. Interventions such as wound and lymphoedema management and surgery (mainly debridement and skin grafting) should be used as needed to speed up healing, thereby shortening the duration of hospitalization. Physiotherapy is required in severe cases to prevent disability. Patients left with disability require long-term rehabilitation. These same interventions are applicable to other NTDs such as leprosy and lymphatic filariasis, and should be made accessible to patients through implementation of WHO's integrated skin NTD approach *(13)* and the WHO morbidity management and disability prevention aide-mémoire *(14)*.

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