
Lyme Disease

Identification

1. Indicator Description

This indicator looks at the incidence of Lyme disease in the United States since 1992. Lyme disease is a tick-borne bacterial illness that can cause fever, fatigue, and joint and nervous system complications. It is one of several tick- or mosquito-borne diseases that the Centers for Disease Control and Prevention (CDC) tracks (CDC, 2024; Rosenberg et al., 2018). The spread of Lyme disease is affected by tick prevalence; populations and infection rates among host species; human population patterns, awareness, and behavior; habitat; climate; and other factors. Examining Lyme disease incidence may be useful for understanding the long-term effects of climate change on vector-borne diseases, as shorter-term variations in weather have less of an impact on ticks than on other disease vectors such as mosquitoes. This is the case for several reasons (Ogden et al., 2013):

- Ticks have a relatively long-life cycle, including stages of development that take place in the soil, where temperatures fluctuate less than air temperatures.
- Tick development rates have a delayed response to temperature changes, which minimizes the effects of short-term temperature fluctuations.
- Ticks can take refuge in the soil during periods of extreme heat, cold, drought, or rainfall.
- Ticks are associated with woodland habitats, where microclimates are buffered from temperature extremes that occur in treeless areas.
- Unlike other disease vectors such as mosquitoes, ticks do not have nonparasitic immature feeding stages whose survival is susceptible to short-term changes in weather.

Consequently, in some locations in the United States, Lyme disease incidence would be expected to increase with climate change.

Components of this indicator include:

- Annual incidence of Lyme disease in the United States, 1992–2022 (Figure 1).
- Reported Lyme disease incidence by state in 2022 (Figure 2).
- Change in incidence and distribution of reported cases of Lyme disease in the United States, 1996 and 2022 (Figure 3).

2. Revision History

May 2014:	Indicator published.
June 2015:	Updated indicator with data through 2013.
August 2016:	Updated indicator with data through 2014.
April 2021:	Updated indicator with data through 2018.
December 2024:	Updated indicator with data through 2022. Revised all figures to align with the 2022 case definition for Lyme disease and changes in surveillance methods over time.

Data Sources

3. Data Sources

This indicator is based on annual numbers of reported total (confirmed and probable) Lyme disease cases, nationally and by state, compiled by CDC's Division of Vector-Borne Diseases. Incidence was calculated using the most recent mid-year population estimates for each year from the U.S. Census Bureau. The county-level data for the 1996 and 2022 comparison maps in Figure 3 also came from CDC.

4. Data Availability

All of the data for this indicator are publicly available on CDC and Census Bureau websites.

EPA obtained the data for this indicator from CDC's website. Prior to 2008, CDC compiled only confirmed cases, but in 2008 it also began to track probable (but unconfirmed) cases. CDC's database allows users to query the total (confirmed and probable) cases, which EPA used for this indicator.

Although some data are available starting in 1990, this indicator starts in 1992 because Lyme disease did not become an official nationally reportable disease until January 1991, and CDC has determined that 1992 was the first year with sufficiently complete data for trend analysis.

CDC's national and state-level data are available online. The 1993–1995 national case counts have been published in CDC's Morbidity and Mortality Weekly Reports (MMWR), which are available at: www.cdc.gov/mmwr/mmwr_nd/index.html. Data for 1992 had also been published in MMWR but were updated at: https://lymediseaseassociation.org/LDA_Apps/content/Maps. National data from 1996 onward and state-level data from 2008 onward are available in tabular form at: www.cdc.gov/lyme/data-research/facts-stats/surveillance-data-1.html. Finalized data from 2016 onward are also available at: <https://wonder.cdc.gov> for every reportable condition, including Lyme disease. County-level data from 2001 to 2022 are available at: www.cdc.gov/lyme/data-research/facts-stats/lyme-disease-case-map.html, covering all cases for which the patient's county of residence was recorded. Annual maps of reported cases of Lyme disease from 2001 to 2022 are also posted online at: www.cdc.gov/lyme/data-research/facts-stats/lyme-disease-case-map.html. CDC staff provided the analogous 1996 dot map to EPA.

Following CDC's standard practice, incidence has been calculated using population estimates on July 1 of each calendar year. These population estimates are publicly available from the U.S. Census Bureau's Population Estimates Program. Data are available at: www.census.gov/programs-surveys/popest/data/tables.All.html.

Methodology

5. Data Collection

This indicator is based on the annual reported number of Lyme disease cases as compiled by CDC.

State and local health departments report weekly case counts for Lyme disease following CDC's case definitions through the NNDSS. The NNDSS is a public health system for the reporting of individual cases

of disease and conditions to state, local, and territorial health departments, which then forward case information to CDC. The provisional state-level data are reported in CDC's MMWR. After all states have verified their data, CDC publishes an annual surveillance summary for Lyme disease and other notifiable diseases.

Health care providers report information to local or state health departments. From there, public health personnel classify each case as confirmed, probable, suspect, or not a case. Health departments nationwide follow a standardized definition for what constitutes a "confirmed" case and a "probable" case of Lyme disease, but these definitions have changed over time (see Section 8). The first standardized surveillance case definition was established in 1990 by the Council of State and Territorial Epidemiologists (CSTE). In January 1991, Lyme disease became a nationally notifiable disease in the United States, using the CSTE's 1990 definition. As such, state and local health departments work with health care providers to obtain case reports for Lyme disease based upon the CSTE case definition.

6. Indicator Derivation

Figure 1. Reported Cases of Lyme Disease in the United States, 1992–2022

National incidence of Lyme disease was calculated using the number of confirmed Lyme disease cases and the national population for each year from 1992 through 2007. In 2008, CDC began tracking probable cases in addition to confirmed cases. For each year from 2008 through 2022, national incidence of Lyme disease was calculated using the total number of confirmed and probable cases and the national population. EPA calculated incidence by dividing the total number of cases per year by the corresponding population on July 1 in the same calendar year. CDC and EPA then multiplied the per-person rate by 100,000 to generate a normalized incidence rate per 100,000 people. This is CDC's standard method of expressing the incidence of Lyme disease.

Figure 1 contains three breakpoints, which divide the time series into four segments. Section 8, "Comparability Over Time and Space," describes the changes in case definitions and reporting procedures that created these discontinuities in the data.

Figure 2. Reported Lyme Disease Cases by State, 2022

Figure 2 shows the reported incidence of Lyme disease by jurisdiction in 2022 for the 50 states and the District of Columbia. Incidence is calculated as a rate per 100,000 people, as described for Figure 1. Section 8 explains differences in what was counted as a "case," depending on whether CDC has determined the jurisdiction to be "high-incidence" or "low-incidence."

Figure 3. Change in Incidence and Distribution of Reported Cases of Lyme Disease in the United States, 1996 and 2022

This comparison uses two maps—one for the year 1996 and one for the year 2022—to illustrate changes in the incidence and distribution of reported cases of Lyme disease in the United States over time. EPA chose 1996 at CDC's recommendation because it was the first year after a significant case definition change that incorporated recommended testing approaches. Each dot on the maps represents an individual case placed randomly within the patient's county of residence, which may differ from the county of exposure.

Indicator Development

In the course of developing and revising this indicator based on peer review and comments from CDC experts, EPA considered several ways to present the data. For example:

- The incidence of a disease can be tracked with total case counts or with incidence rates that are normalized by population size. EPA chose to display rates for this indicator so as to eliminate state-to-state population differences and changes in population over time as confounding factors. This approach is also consistent with data for EPA's Heat-Related Deaths indicator, which is displayed using incidence rates.
- EPA considered focusing the analysis of reported Lyme disease on a subset of jurisdictions. One approach was to consider the high-incidence jurisdictions as defined by CDC. EPA chose to present all 50 states and the District of Columbia to show readers the geographic distribution of reported Lyme disease as in Figures 2 and 3. However, there is scientific evidence (e.g., Diuk-Wasser et al., 2012; Stromdahl & Hickling, 2012) that notes the geographic differences in *Ixodes scapularis* (the deer tick or blacklegged tick) in North America—and that increases in Lyme disease cases in many states south of 35°N latitude are likely due to non-climate-related expansion of northern *I. scapularis* tick genotypes. Analyzing data for a set of states in the northern part of the range of *I. scapularis* might lead to better understanding of changes in Lyme disease cases as they relate to a warming climate. Thus, future work on this indicator will attempt to reflect the effects of climate change on expansion in the range of *I. scapularis*, increasing abundance of *I. scapularis* where it already occurs, increases in the prevalence of *Borrelia burgdorferi* (the bacteria that actually cause Lyme disease) in host-seeking ticks, and/or updated understanding of other known environmental drivers, such as deer density and changes in landscape, habitat, and biodiversity.

A previous version of this indicator included data from 1991. During the 2024 indicator update, CDC advised EPA that in their most recent re-analyses, they had found 1991 data to be insufficiently complete for trend analysis. Because 1991 was the first year of somewhat systematic data collection for Lyme disease, data were reported as aggregate numbers by state instead of broken out more granularly, and some historical source records were found to conflict with each other. As a result, EPA revised Figure 1 to use 1992 as a starting point. EPA also made other revisions in 2024 as a result of changes to CDC's source data and case definition. These changes included reformatting Figure 1 as a column chart with clear discontinuities at each major case definition change and converting Figure 2 from a trend map to a single-year snapshot because the data are no longer comparable over time.

7. Quality Assurance and Quality Control

Each state has established laws mandating that health providers report cases of various diseases (including Lyme disease) to their health departments. Each state health department verifies its data before sharing them with CDC. The NNDSS is the primary system by which health surveillance data are conveyed to CDC for national-level analyses.

Starting in 1990, CDC launched the National Electronic Telecommunications System for Surveillance (NETSS), replacing mail and phone-based reporting. In 2000, CDC developed the National Electronic Disease Surveillance System (NEDSS) Base System (NBS). This central reporting system sets data and

information technology standards for departments that provide data to CDC, ensuring that data are submitted quickly, securely, and in a consistent format.

Using CSTE case definitions, CDC provides state and local health departments and health providers with comprehensive guidance on laboratory diagnosis and case classification criteria, ensuring that all health providers and departments classify Lyme disease cases consistently throughout the United States.

State health officials use various methods to ascertain cases, including passive surveillance initiated by health care providers, laboratory-based surveillance, and “enhanced or active surveillance” (Bacon et al., 2008). State officials check the data and remove duplicate reports before submitting annual totals to CDC.

CDC has undertaken a review of alternative data sources to see how closely they align with the disease counts captured by the NNDSS. These alternative sources include medical claims information from a large insurance database, a survey of clinical laboratories, and a survey that asks individuals whether they have been diagnosed with Lyme disease in the previous year. Results from this review suggest that the NNDSS may be undercounting the true number of cases of Lyme disease (CDC, 2013). A more recent analysis based on insurance data came to a similar conclusion (Kugeler et al., 2021). See Section 10 for further discussion about this possible source of uncertainty.

Analysis

8. Comparability Over Time and Space

Lyme disease data collection follows CDC’s case definition to ensure consistency and comparability across the country. The national case definition for Lyme disease has changed several times since Lyme disease became a notifiable disease: in 1996, 2008, 2011 (less significantly), 2017, and 2022. Prior to 1996, a confirmed case of Lyme disease required only a skin lesion with the characteristic “bull’s-eye” appearance. In 1996, CDC expanded the definition of confirmed cases to include laboratory-confirmed, late-manifestation symptoms such as issues with the musculoskeletal, nervous, and cardiovascular systems. In 2008, the case classifications were expanded again to include suspected and probable cases.

In 2017, CDC established designations for “high-incidence” and “low-incidence” jurisdictions. While this change alone does not require a discontinuity in Figure 1, the subsequent change in 2022 does, because that is when CDC updated the case definition to allow for different surveillance practices in “high-incidence” and “low-incidence” jurisdictions. High-incidence jurisdictions have had an average Lyme disease incidence equal to or greater than 10 confirmed cases per 100,000 people for a period of three consecutive years. Once a low-incidence jurisdiction meets the criterion for high incidence, it permanently becomes a high-incidence jurisdiction for the purpose of Lyme disease surveillance. As of 2022, the high-incidence jurisdictions are:

- Connecticut
- Delaware
- District of Columbia
- Maine
- Maryland

- Massachusetts
- Minnesota
- New Hampshire
- New Jersey
- New York
- Pennsylvania
- Rhode Island
- Vermont
- Virginia
- West Virginia
- Wisconsin

These 16 jurisdictions collectively represented about 95 percent of the nation’s reported cases of Lyme disease in 2022.

High-incidence jurisdictions can report cases to CDC based on laboratory evidence alone, without additional clinical confirmation. This allowance is important for completeness of the data, because the previous requirement to collect clinical evidence had created a large administrative burden in high-incidence jurisdictions. As a result, some state and local agencies were unable to report “confirmed” cases, which artificially lowered the apparent case counts. Thus, to reduce the reporting burden from the large number of Lyme disease cases, collection of clinical evidence in high-incidence jurisdictions is no longer a requirement. Clinical evidence is still needed to classify cases in low-incidence jurisdictions as “confirmed.” The “probable” case classification in low-incidence jurisdictions was restricted and updated to require clinical information as well. The apparent increase in Lyme disease incidence in 2022 is likely the result of these data collection changes rather than a change in disease risk (Kugeler et al., 2024).

These definition changes necessitate careful comparisons of data from multiple years. Although the case definition changes have improved Lyme disease surveillance, they prevent detailed comparison with historical data and accurate analysis of trends over time. It is not possible to control for the case definition changes.

In addition to the national changes, several state and local reporting agencies have changed their own data collection and reporting practices at various times. These jurisdiction-level changes include California in 2005, Connecticut in 2003, the District of Columbia in 2011, Hawaii in 2006, New Hampshire in 2014, New York in 2007, Rhode Island in 2004, and Wisconsin in 2012. In several jurisdictions that are high-incidence, reporting requirements were reduced as a result of resource constraints. However, the revised case definition in 2022 improved the standardization of surveillance and reporting practices across high-incidence jurisdictions. The extent to which jurisdiction-level changes affect overall comparability over time and space is unknown. Figure 2 only shows annual Lyme disease incidence by jurisdiction for 2022 because the changes in surveillance have diminished confidence in any apparent jurisdiction-level trends over time.

9. Data Limitations

Factors that may have an impact on the confidence, application, or conclusions drawn from this indicator are as follows:

1. Changes in diagnosing practices and awareness of the disease over time can affect Lyme disease trends.
2. CDC's national Lyme disease case definitions have changed multiple times since Lyme disease became a notifiable disease. As discussed in Section 8, it is not possible to control for the case definition changes, which adds some uncertainty to the indicator. Some state and local agencies have also changed their data collection and reporting practices at various times, as described in Section 8.
3. As described in Section 10, public health experts believe that many cases of Lyme disease are not reported, which means this indicator underestimates the true incidence of the disease (CDC, 2013; Kugeler et al., 2021). The reporting rate may vary over time and space as a result of differences in funding and emphasis among state surveillance programs. In addition, Lyme disease can be difficult to diagnose. Cases in locations where Lyme disease is not endemic are at particular risk of being unidentified or misdiagnosed.
4. Reporting Lyme disease cases based on laboratory evidence alone might lead to overreporting due to the inclusion of past infections and cases incompatible with clinical criteria. Previous Lyme disease infections can continue to produce positive laboratory test results for months to years after treatment (Kugeler et al., 2024).
5. Laboratory tests for Lyme disease have changed and become more effective over time. New tests with higher sensitivity might increase the number of patients with positive laboratory test results. However, health departments have reported difficulty identifying the results of new Lyme disease tests in their case reporting systems, which might conversely lead to underreporting (Kugeler et al., 2024). CDC has indicated that newly implemented lab reporting (LOINC) codes should reduce this challenge for reporting years 2023 and beyond.
6. As an indicator of climate change, Lyme disease is limited due to several confounding factors:
 - Tick control efforts and public health education could counteract the growth of confirmed cases expected due to warming climates, although more study is needed to determine how effective these solutions can be.
 - Importantly, there are several factors driving changes in incidence of Lyme disease other than climate. Several of these factors have not been well-quantified or studied. Possible factors include range expansion of vector ticks, which is not always climate-related; proximity of hosts; changes in deer density; changes in biodiversity; and the effects of landscape changes such as suburbanization, deforestation, and reforestation.
 - Pathogen transmission is affected by several factors including geographic distribution, population density, prevalence of infection by zoonotic pathogens, and the pathogen load within individual hosts and vectors (e.g., Cortinas & Kitron, 2006; Lingren et al., 2005; Mills et al., 2010; Raizman et al., 2013).

- Human exposure depends upon behavior with at-risk activities, socioeconomic and cultural factors, land use, health care access, and living conditions (Gage et al., 2008; Gubler et al., 2001; Hess et al., 2012; Lafferty, 2009; Wilson, 2009).
7. Lyme disease surveillance data capture the county of residence, which is not necessarily the location where an individual was infected.
 8. The COVID-19 pandemic affected the data presented in 2019, 2020, and 2021 in several ways:
 - The following 23 jurisdictions may have incomplete 2019 data: Alaska, California, Connecticut, Delaware, District of Columbia, Florida, Idaho, Indiana, Kansas, Massachusetts, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New York, North Dakota, Ohio, Oklahoma, South Carolina, Tennessee, Texas, and West Virginia. Data for 2019 are affected because health agencies would have compiled and reported those results during 2020, when they instead had to focus resources on the COVID-19 pandemic.
 - The following six jurisdictions may have incomplete 2020 data: California, Idaho, Kansas, Maryland, Minnesota, and Vermont.
 - In 2020 and 2021, the impacts of the COVID-19 pandemic on Lyme disease incidence included changes in the time spent outdoors and the probability of tick encounters, how many people sought health care and were tested for Lyme disease, and the ability of state and local health departments to investigate and report cases (McCormick et al., 2021). Survey data suggest that U.S. residents spent more time outdoors in 2020 compared with 2019, but there were fewer emergency department visits for tick bites and fewer laboratory tests performed. State and local health departments reported fewer cases of Lyme disease in 2020 and 2021, which likely reflects the impacts of the pandemic rather than a true change in disease risk.

10. Sources of Uncertainty

The main source of uncertainty for this indicator stems from its dependence on surveillance data. Surveillance data can be subject to underreporting, overreporting, and misclassification. Because clinical symptoms are a factor in determining Lyme disease, lack of symptoms or delayed symptoms may result in overlooked or misclassified cases. Furthermore, surveillance capabilities can vary from state to state, or even from year to year based upon budgeting and personnel.

Although Lyme disease cases are supposed to be reported to the NNDSS, reporting is actually voluntary. As a result, surveillance data for Lyme disease do not provide a comprehensive determination of the U.S. population with Lyme disease. For example, it has been reported that the annual total number of people diagnosed with Lyme disease may be as much as 10 times higher than the surveillance data indicate (CDC, 2013). Another analysis of medical insurance claims for Lyme disease diagnosis and treatment estimated 476,000 cases per year (Kugeler et al., 2021)—about eight times the number of reported total cases in 2022 according to the source data for this indicator. Consequently, this indicator provides an illustration of trends over time, not a measure of the exact number of Lyme disease cases in the United States.

Another issue is that surveillance data are captured by county of residence rather than county of exposure. Reports of Lyme disease may therefore occur in states with no active pathogen populations. For example, a tourist may be infected with Lyme disease while visiting Connecticut (an area with high incidence of Lyme disease) but not be identified as a Lyme disease case until the tourist returns home to Florida (an area where blacklegged ticks cannot survive). This may result in underreporting in areas of high Lyme disease incidence and overreporting in areas of low Lyme disease incidence.

For a discussion of the uncertainties associated with the U.S. Census Bureau’s intercensal estimates, see: www.census.gov/programs-surveys/popest/technical-documentation/methodology.html.

11. Sources of Variability

The incidence of Lyme disease is likely to display variability over time and space due to:

- Changes in populations of blacklegged ticks and host species (e.g., deer, mice, birds) over time.
- Spatial distribution of blacklegged ticks and changes in their distribution over time.
- The influence of climate on the activity and seasonality of the blacklegged tick.
- Variability in human population and behavior over time and space.

This indicator accounts for these factors by presenting national- and state-scale data and by presenting several decades of data in Figure 1.

12. Statistical/Trend Analysis

This indicator does not report on the slope or average rate of change in Lyme disease incidence over time, nor does it calculate the statistical significance of these trends. This is primarily due to changes in the Lyme disease case definition, which prevent accurate analysis of trends.

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