WHITE PAPER

Trends and Patterns in Lyme Disease

An Analysis of Private Claims Data

A FAIR Health White Paper, December 2019

Summary

Lyme disease is a growing public health issue. FAIR Health analyzed recent data from its repository of over 30 billion privately billed healthcare claims to identify trends and patterns related to Lyme disease and compare such trends and patterns to those in other tick-borne diseases. Among the findings:

- **Increase.** Over about the last decade, Lyme disease increased nationally 117 percent, from 0.027 percent of all medical claim lines in 2007 to 0.058 percent in 2018.
- **Predominance.** Claim lines for Lyme disease accounted for 94 percent of claim lines for tick-borne diseases in 2018.
- **Urban versus rural.** Growth in Lyme disease claim lines from 2007 to 2018 was more pronounced in urban than rural areas.
- **Monthly distribution.** In 2018, the months with the highest share of the distribution of claim lines for Lyme disease were June (10.7 percent) and July (11.0 percent). The months with the lowest share were December (6.2 percent) and February (6.5 percent).
- **Geographic spread.** In 2007, the five states with the highest number of claim lines with Lyme disease diagnoses as a percentage of all medical claim lines by state were all in the Northeast, but in 2018, one (North Carolina) was in the South.
- **Age.** In both rural and urban areas in 2018, individuals aged 51 to 60 held the largest share of the age distribution of claim lines with Lyme disease diagnoses. The age group 41-50 held the second largest share in both rural and urban areas.
- **Gender.** In both rural and urban areas in 2018, more claim lines with Lyme disease diagnoses were submitted for females than males.
- **Age and gender.** In 2018, more claim lines for Lyme disease were submitted for females than males in every age group from 11 to 70, but in the youngest and oldest segments (0-10 and over 70), more claim lines were submitted for males.
- **Places of service.** The laboratory was the place of service with the largest share of Lyme disease claim lines in both 2014 and 2018. The office held the second largest share both years.
- **Procedures.** By percent of patients, the most common procedure performed for patients with a Lyme disease diagnosis in 2018 was a 15-minute office or other outpatient visit for an established patient. Among the top five procedures by volume, the procedure that was performed the most times per Lyme disease patient was 45-minute psychotherapy.
- **Other diagnoses.** In 2018, the 10 most common "other diagnoses" found in patients who had been diagnosed with Lyme disease were, in order from most to least common, general signs and symptoms, dorsopathies, soft tissue disorders, other joint disorders, disorders of the thyroid gland, anxiety and other nonpsychotic mental disorders, osteoarthritis, skin and subcutaneous tissue symptoms, dermatitis and eczema, and mood (affective) disorders. All were more common in patients with Lyme disease than in all patients.

Background

Lyme disease is an illness of increasing national concern. According to the Centers for Disease Control and Prevention (CDC), confirmed cases of Lyme disease rose 131 percent from 1997 to 2017.[1] The CDC estimates that approximately 300,000 people are diagnosed with Lyme disease each year in the United States, with cases concentrated in the Northeast and upper Midwest.[2]

Lyme disease is usually caused by the bacterium *Borrelia burgdorferi*; more rarely, *Borrelia mayonii* is the cause.[3] The disease is transmitted to humans through the bite of infected blacklegged ticks (*Ixodes*

[1] Centers for Disease Control and Prevention (CDC), "Lyme Disease Charts and Figures: Historical Data," last reviewed December 21, 2018, https://www.cdc.gov/lyme/stats/graphs.html.
[2] CDC, "How Many People Get Lyme Disease?," last reviewed December 21, 2018, https://www.cdc.gov/lyme/stats/humancases.html.
[3] CDC, "Lyme Disease," last reviewed November 8, 2019, https://www.cdc.gov/lyme/index.html.

scapularis and *Ixodes pacificus*),[4] typically in grassy, brushy or wooded areas.[5] Early symptoms of Lyme disease include fever, fatigue, headache and a rash (erythema migrans) that may look like a bull's eye.[6] The disease can be treated with antibiotics, but if allowed to go untreated, it can affect joints, the nervous system and the heart.

Even if Lyme disease is treated, some patients experience a long-term illness, post-treatment Lyme disease syndrome (PTLDS), sometimes called chronic Lyme disease.[7,8] Its symptoms include fatigue, joint and muscle pain, and cognitive issues.[9] The cause is not well understood. Some researchers believe the illness may be due to an autoimmune reaction to the previous infection, some to a persistent but hard to detect infection and some to unrelated causes.

Lyme disease is the nation's most common vector-borne disease, a type of illness transmitted by intermediary organisms such as mosquitoes, ticks and fleas.[10] In the United States from 2004 to 2016, tick-borne diseases—including, most prominently, Lyme disease—accounted for about 75 percent of reported cases of vector-borne diseases. Vector-borne diseases have been increasing in the United States and globally.[11] Possible causes in the United States include increases in urban and suburban development, shifting patterns of travel and recreation, and climate change.[12,13]

As part of the 21st Century Cures Act of 2016, Congress established the Tick-Borne Disease Working Group to provide subject-matter expertise and review federal efforts related to tick-borne diseases, to help ensure interagency coordination and minimize overlap, and to examine research priorities.[14] The Working Group became aware of FAIR Health's research on Lyme disease, which had been published in the form of an infographic[15] and article.[16] A national, independent nonprofit organization dedicated to bringing transparency to healthcare costs and health insurance information, FAIR Health possesses the nation's largest repository of privately billed healthcare claims—over 30 billion claim records from 2002 to the present. That repository provides a unique window into Lyme and other tick-borne diseases. At the invitation of the Working Group's Subcommittee on Training, Education, Access to Care and

---

[4] CDC, "Lyme Disease—Transmission," last reviewed February 6, 2019, https://www.cdc.gov/lyme/transmission/index.html.
[5] CDC, "Stop Ticks to Avoid Lyme and Other Tickborne Diseases," last reviewed May 14, 2019, https://www.cdc.gov/features/stopticks/index.html.
[6] CDC, "Lyme Disease."
[7] CDC, "Post-Treatment Lyme Disease Syndrome," last reviewed November 8, 2019, https://www.cdc.gov/lyme/postlds/index.html.
[8] Adriana Marques, "Chronic Lyme Disease: A Review," *Infectious Disease Clinics of North America* 22, no. 2 (June 2008): 341-60, https://doi.org/10.1016/j.idc.2007.12.011.
[9] CDC, "Post-Treatment Lyme Disease Syndrome."
[10] Ronald Rosenberg et al., "*Vital Signs*: Trends in Reported Vectorborne Disease Cases—United States and Territories, 2004–2016," *Morbidity and Mortality Weekly Report* 67, no. 17 (May 4, 2018): 496-501, https://www.cdc.gov/mmwr/volumes/67/wr/pdfs/mm6717e1-H.pdf.
[11] World Health Organization, "World Health Assembly Approves Comprehensive Global Approach against Vector-Borne Diseases," June 2, 2017, https://www.who.int/neglected_diseases/news/comprehensive_global_approach_against_vector-borne_diseases/en/.
[12] Kim Krisberg, "Vector-Borne Diseases Growing as Threats to U.S. Public Health: Climate Change, Travel Linked to Illness," *The Nation's Health* 40, no. 7 (September 2010): 1-21, http://thenationshealth.aphapublications.org/content/40/7/1.2.
[13] "Vector-Borne Diseases in the United States," SciLine, last updated April 15, 2019, https://www.sciline.org/evidence-blog/vector-borne-diseases.
[14] US Department of Health & Human Services, Office of the Assistant Secretary for Health, "Tick-Borne Disease Working Group," last reviewed February 21, 2018, https://www.hhs.gov/ash/advisory-committees/tickbornedisease/index.html.
[15] FAIR Health, *Lyme Disease: A Growing Concern*, A FAIR Health Infographic, July 2017, https://s3.amazonaws.com/media2.fairhealth.org/infographic/asset/FH%20Infographic%20-%20Lyme%20Disease.pdf.
[16] Robin Gelburd, "A Window into Lyme Disease Using Private Claims Data," *American Journal of Managed Care*, July 27, 2017, https://www.ajmc.com/contributor/robin-gelburd-jd/2017/07/a-window-into-lyme-disease-using-private-claims-data.

Reimbursement, FAIR Health presented a webinar on October 18, 2019, offering new findings on Lyme disease for consideration by the subcommittee. Those findings are now presented to a wider audience in this white paper.[17]

This study compares Lyme disease to other tick-borne diseases, noting their different trends and patterns in rural versus urban areas. Among the topics of analysis are multiyear trends, monthly distribution, state distribution, age and gender, places of service, procedures, and other diagnoses found in patients who have been diagnosed with Lyme disease.

Methodology

FAIR Health analyzed private insurance claims associated with Lyme disease and other tick-borne disease diagnoses, evaluated claim characteristics (such as age and gender of patient and location of service) and examined procedure codes reported on claims. Trends and patterns in utilization were then identified.

Using the International Classification of Diseases (ICD-9-CM and ICD-10-CM) diagnostic codes reported on claims in the FAIR Health dataset, FAIR Health examined claims that were indicative of Lyme disease (e.g., ICD-9-CM 088.81, Lyme disease, and ICD-10-CM A69.2, Lyme disease, unspecified) and other tick-borne diseases (e.g., ICD-9-CM 082.0, tick-borne spotted fevers [including Rocky Mountain spotted fever], and ICD-10-CM B60.0, babesiosis).

Data were then evaluated by stratifying them by gender and age, as well as by a combination of the US Census Bureau's classification categorizations, including the urban-rural data, and the FAIR Health geozip paradigm, which divides the United States into 493 separate geographic regions, to provide results by state.

Analysis was conducted on CPT® codes[18] (maintained by the American Medical Association) and HCPCS Level II codes (maintained by the Centers for Medicare & Medicaid Services), such as those for office or outpatient services (e.g., CPT 99214, office outpatient visit for established patient, 25 minutes), laboratory services (e.g., CPT 84443, blood test for thyroid-stimulating hormone [TSH]) and psychotherapy (e.g., CPT 90834, psychotherapy, 45 minutes with patient and/or family member).

The data were aggregated by a variety of key fields, including diagnostic code categories—both at a mid-level and granular level based on ICD chapter definitions (e.g., general signs and symptoms is a mid-level diagnosis, while malaise and fatigue is a granular diagnosis). Other key fields included state, gender, age and year of service. The aggregation was done to identify trends and patterns in utilization as well as patient correlations. The data were evaluated with single and multiple variables to look for distinct trends, associations and correlations.

In the graphical representations below, the term "claim lines" refers to the individual procedures or services listed on an insurance claim. (The terms "procedures" and "services" are used interchangeably in this report.) One patient may have multiple claim lines. "Percent of claim lines" is the percent of all claim lines associated with a given grouping of diagnosis codes (e.g., codes associated with Lyme disease) in a given time period (e.g., 2007-2018).

"Percent of all medical claim lines" refers to the total number of lines that are included in the variable cohort divided by the total number of medical claim lines for either that year or location or both. This is to normalize the data for any fluctuations that can occur with yearly seasonality (e.g., a particularly severe

[17] This white paper does not reflect the opinions of the Tick-Borne Disease Working Group Subcommittee. FAIR Health is solely responsible for the content and conclusions herein.
[18] CPT © 2019 American Medical Association (AMA). All rights reserved.

flu season) or within the data contributions FAIR Health receives (e.g., if FAIR Health receives data from a plan that covers employees of a major retailer, which then shuts down).

“Percent of patients” refers only to data that are trackable for de-identified, specific patients across time via a unique patient identifier, and is the number of patients who meet the criteria for the statistic divided by the total number of unique patients in the denominator cohort.

The FAIR Health dataset includes longitudinal data (data that are trackable for specific patients across time) and nonlongitudinal data. The findings represented in figures 1-19 are based on the entirety of the FAIR Health dataset (both longitudinal and nonlongitudinal data) and the remaining figures (20-31) on longitudinal data only.

The figures based on only longitudinal data compare patients diagnosed with Lyme disease (Lyme patients) to all patients (i.e., all patients including those with and without Lyme disease diagnoses). Lyme patients are those patients in the longitudinal dataset who had at least five claim lines with Lyme disease diagnoses in any two-year period from 2014 to 2018. This was to distinguish patients who were likely to have a genuine diagnosis of Lyme disease from those who were only tested for it.

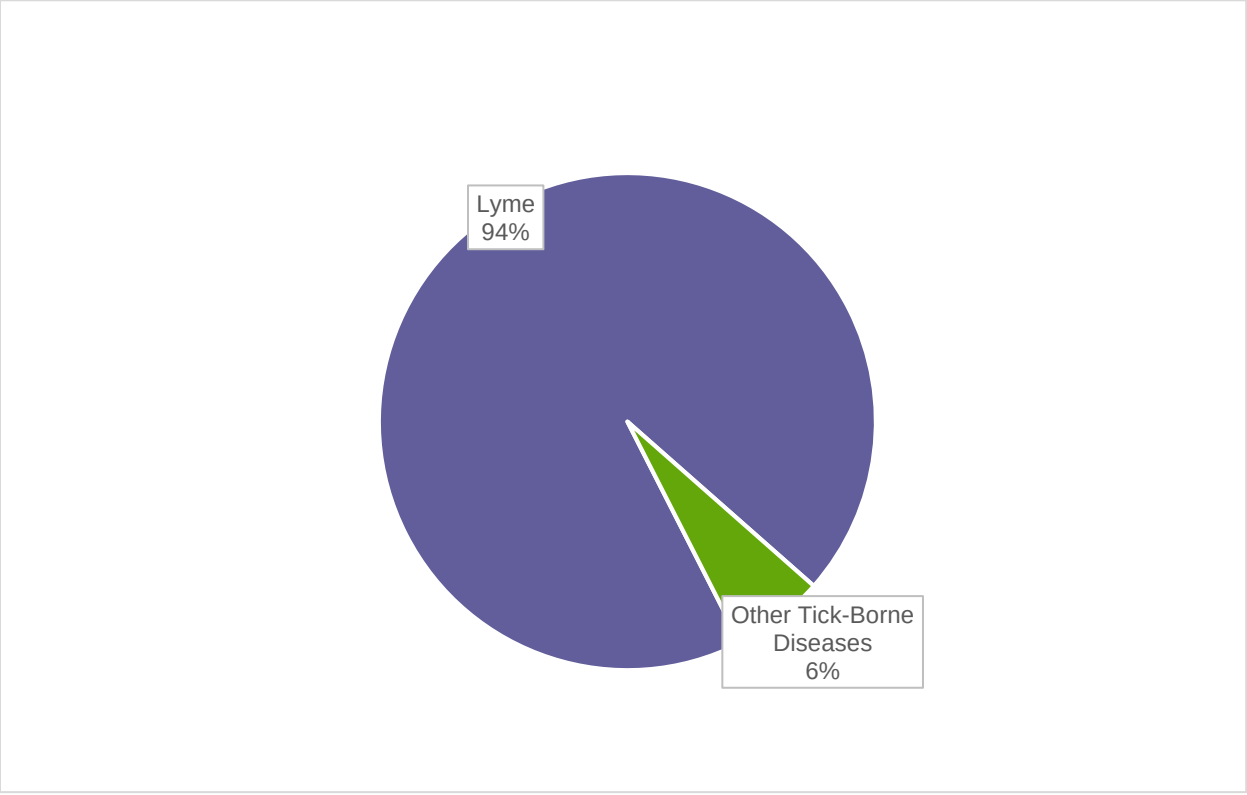


Figure 1. Distribution of claim lines with diagnoses of Lyme disease and other tick-borne diseases, 2018

Lyme Disease versus Other Tick-Borne Diseases

Claim lines for Lyme disease accounted for 94 percent of claim lines for tick-borne diseases in 2018 in the FAIR Health repository, with other tick-borne diseases accounting for 6 percent (figure 1). The

predominance of Lyme disease among tick-borne diseases is in keeping with previous research. According to the CDC, in the United States from 2004 to 2016, Lyme disease accounted for 82 percent of cumulative reported tick-borne disease.[19] The difference between the FAIR Health and CDC findings may be due to differences in methodology. FAIR Health assessed private insurance claim lines in 2018, while the CDC assessed reported cases from 2004 to 2016.

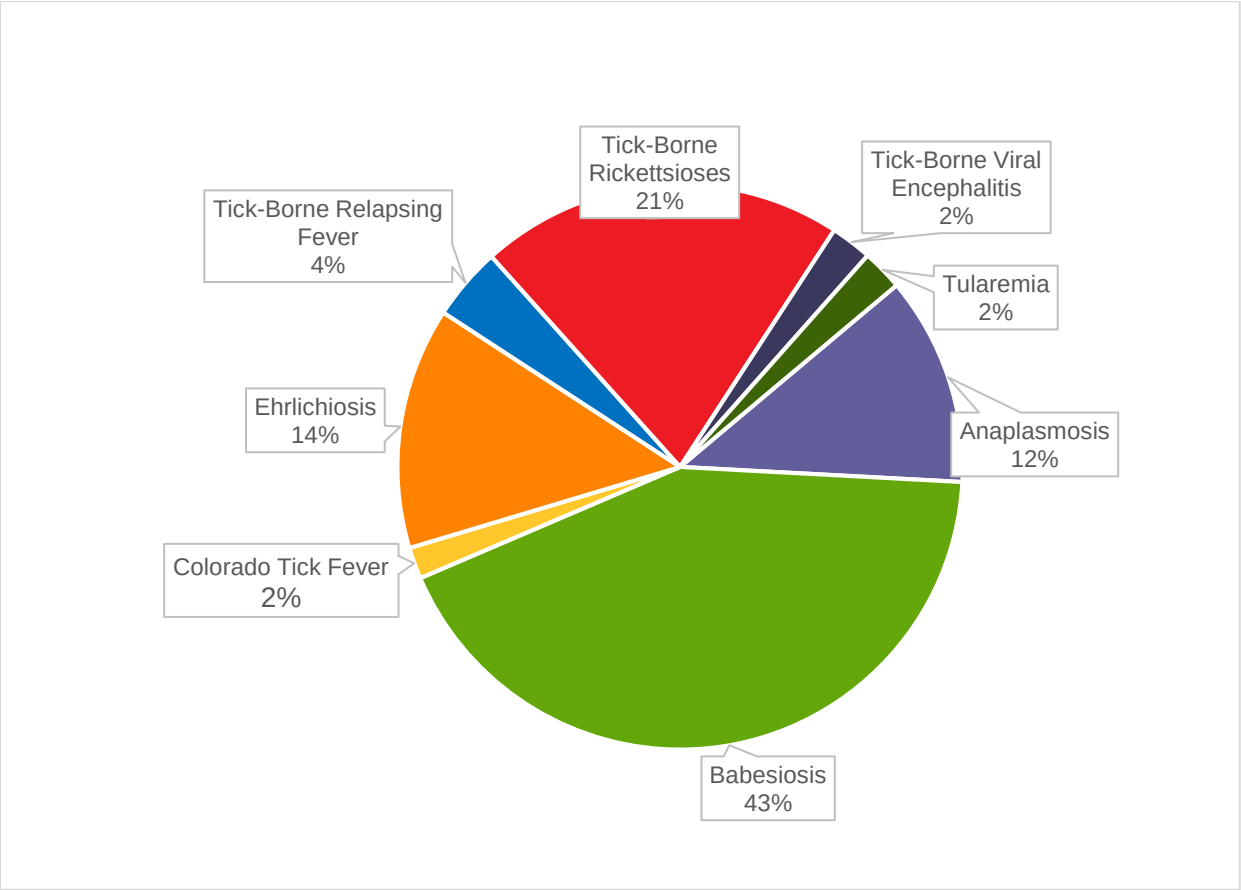


Figure 2. Distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease, 2018

Of tick-borne diseases other than Lyme disease in 2018, babesiosis held the greatest share of claim lines in the FAIR Health repository, at 43 percent (figure 2). Typically caused by *Babesia microti* and transmitted by *Ixodes scapularis* ticks, babesiosis occurs primarily in the Northeast and upper Midwest.[20] Tick-borne rickettsioses constituted the second largest share, at 21 percent. This category includes Rocky Mountain spotted fever, caused by *Rickettsia rickettsii*,[21] and *Rickettsia parkeri* rickettsiosis, caused by the closely related *Rickettsia parkeri*.[22] The third largest share, 14 percent, was held by

[19] Rosenberg et al., "*Vital Signs*: Trends in Reported Vectorborne Disease Cases."
[20] CDC, "Babesiosis," last reviewed January 10, 2019, https://www.cdc.gov/ticks/tickbornediseases/babesiosis.html.
[21] CDC, "Rocky Mountain Spotted Fever (RMSF)," last reviewed January 10, 2019, https://www.cdc.gov/ticks/tickbornediseases/rmsf.html.
[22] CDC, "*Rickettsia Parkeri* Rickettsiosis," last reviewed January 10, 2019, https://www.cdc.gov/ticks/tickbornediseases/rickettsiosis.html.

ehrlichiosis, which is caused by three agents, *Ehrlichia chaffeensis*, *Ehrlichia ewingii* and *Ehrlichia muris eauclairensis*.[23]

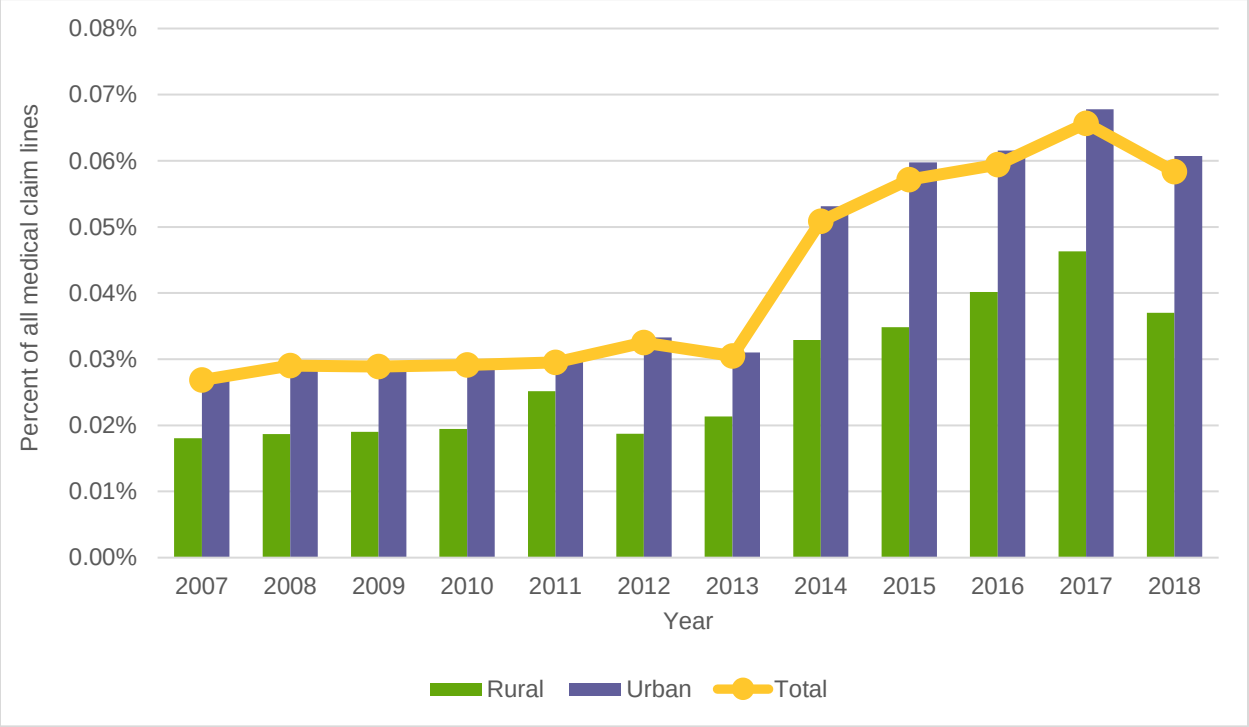


Figure 3. Claim lines with Lyme disease diagnoses as a percentage of all medical claim lines by rural, urban and national areas, 2007-2018

Multiyear Trends 2007-2018

From 2007 to 2018, claim lines with diagnoses of Lyme disease increased nationally 117 percent, from 0.027 percent of all medical claim lines to 0.058 percent (figure 3). The increase is similar to the CDC's 111 percent increase in probable cases of Lyme disease from 2008 (the first year that probable cases were counted) to 2017.[24] The CDC's increase in confirmed cases of Lyme disease from 2007 to 2017 is smaller, at eight percent.

The growth in Lyme disease claim lines in the FAIR Health repository was more pronounced in urban than rural areas. In urban areas, the increase was 121 percent (from 0.027 percent of all medical claim lines in 2007 to 0.061 percent in 2018). In rural areas, the increase was 105 percent (from 0.018 percent of all medical claim lines in 2007 to 0.037 percent in 2018).

Historically, tick-borne diseases have been associated more with rural than urban areas.[25] There are several possible reasons why claim lines from urban areas exceed those from rural areas, and for the greater recent growth of Lyme disease in urban than rural areas. More people from urban areas could be

[23] CDC, "Ehrlichiosis," last reviewed January 10, 2019, https://www.cdc.gov/ticks/tickbornediseases/ehrlichiosis.html.
[24] CDC, "Lyme Disease Charts and Figures: Historical Data."
[25] Jenn Lukens, "Feasting on Rural America: The Spread of Tick-Borne Diseases," *The Rural Monitor*, May 17, 2017, https://www.ruralhealthinfo.org/rural-monitor/tick-borne-diseases/.

going to the country on vacation and picking up an infection that is only diagnosed when they return home to the city. In addition, Lyme disease may be spreading increasingly to suburban and urban areas. Ticks that can transmit Lyme disease have been found in 17 of 24 parks surveyed in New York City.[26]

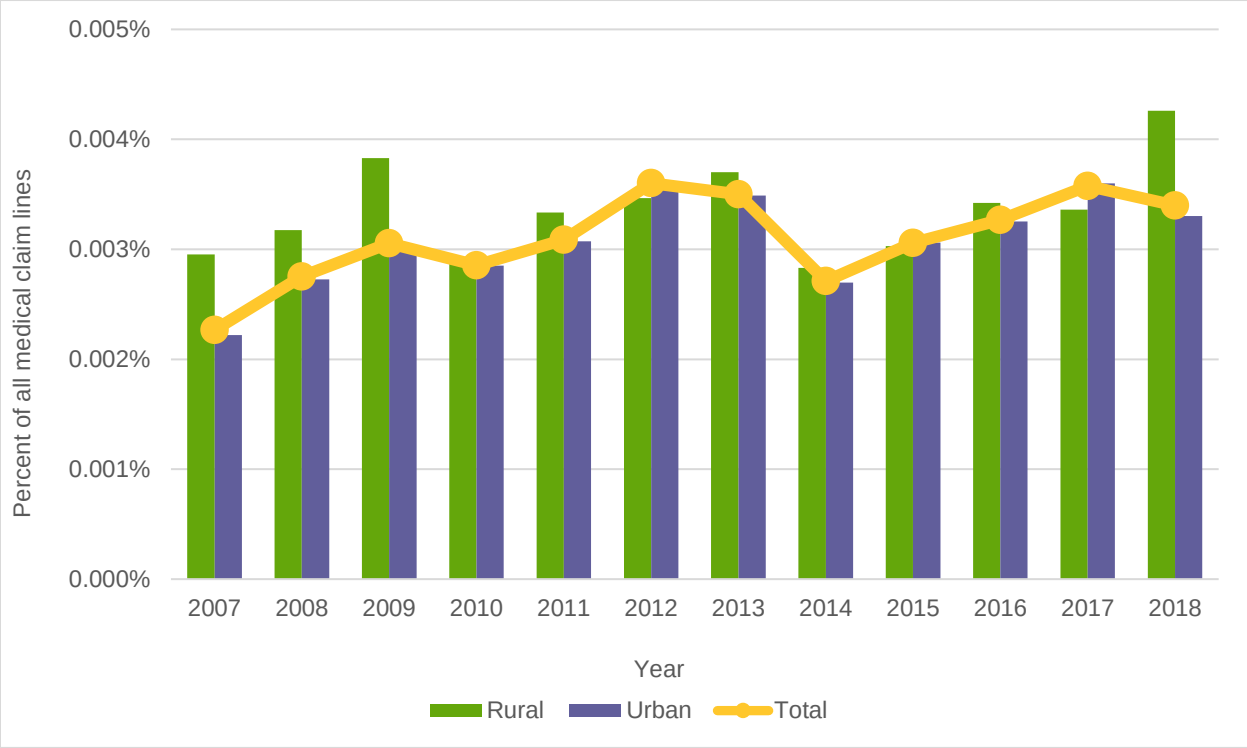


Figure 4. Claim lines with diagnoses of tick-borne diseases other than Lyme disease as a percentage of all medical claim lines by rural, urban and national areas, 2007-2018

Claim lines for tick-borne diseases other than Lyme disease also increased from 2007 to 2018, but not as much (figure 4). The national increase for other tick-borne diseases was 50 percent (compared to 117 percent for Lyme disease), from 0.002 percent of all medical claim lines to 0.003 percent.

Growth in urban and rural areas was more similar for other tick-borne diseases than for Lyme disease. Urban areas showed a 49 percent increase as a percentage of all medical claim lines (from 0.00222 percent in 2007 to 0.00330 percent in 2018). Rural areas showed a 44 percent increase (from 0.00295 percent to 0.00426 percent). For most of the period 2007-2018, and unlike Lyme disease, other tick-borne diseases were diagnosed more frequently in rural than urban areas, although in 2017 they were slightly more prevalent in urban areas.

[26] Meredith C. VanAcker et al., "Enhancement of Risk for Lyme Disease by Landscape Connectivity, New York, New York, USA," *Emerging Infectious Diseases* 25, no. 6 (June 2019): 1136-43, https://doi.org/10.3201/eid2506.181741.

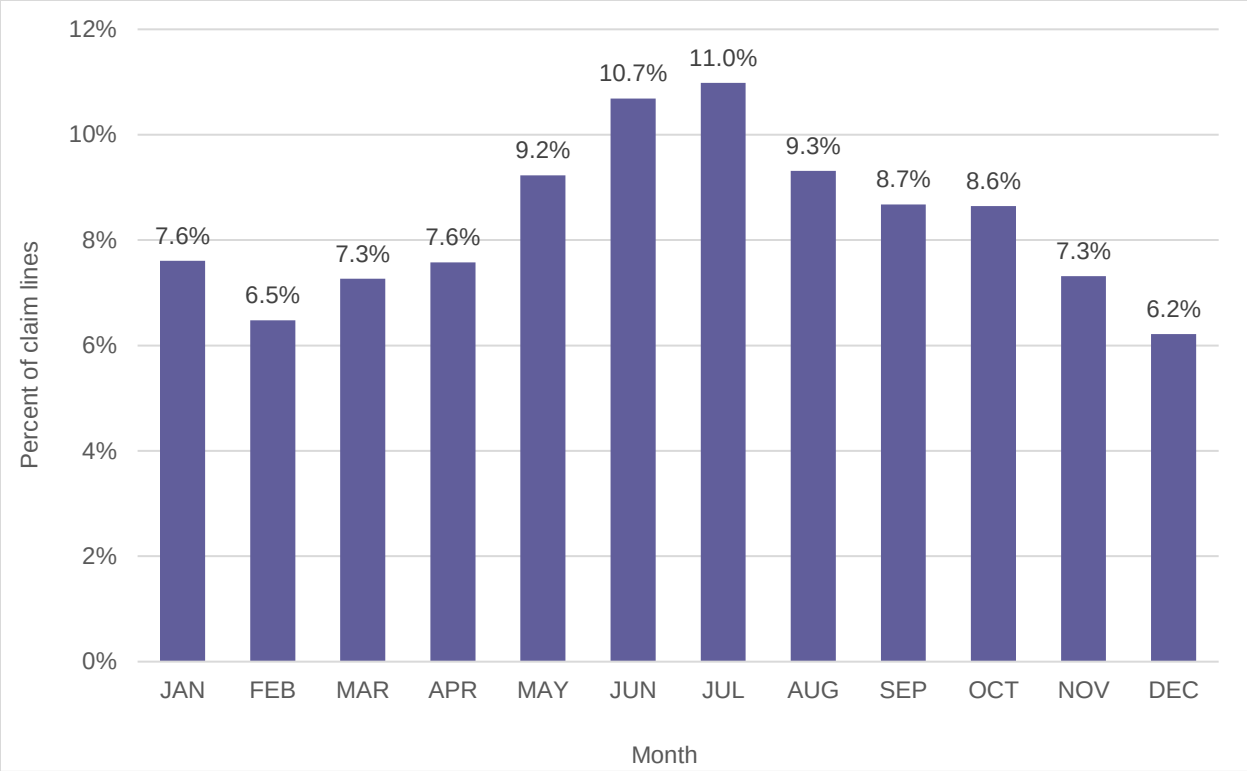


Figure 5. Monthly distribution of claim lines with Lyme disease diagnoses, 2018

Monthly Distribution

In 2018, the months with the highest share of the distribution of claim lines for Lyme disease were June (10.7 percent) and July (11.0 percent; figure 5). The warm months of May through August were generally the peak season for Lyme disease diagnoses. These findings are consistent with CDC data showing that the months from May through August, especially June and July, were the months of highest Lyme disease onset as measured by confirmed cases from 2001 to 2017.[27]

In FAIR Health data, the month with the lowest share of Lyme disease claim lines was December (6.2 percent), followed by February (6.5 percent). This also was similar to CDC data, in which February was the lowest month of disease onset, followed by December.

[27] CDC, "Lyme Disease Charts and Figures: Historical Data."

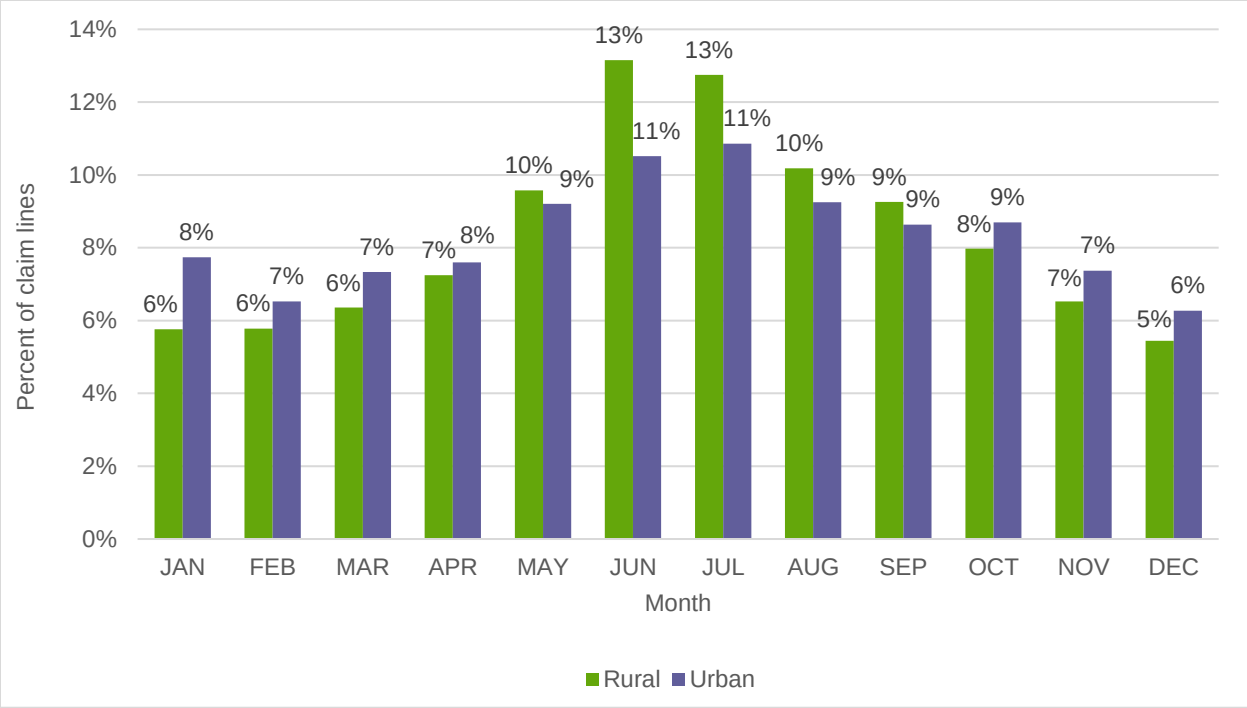


Figure 6. Monthly distribution of claim lines with Lyme disease diagnoses by rural and urban areas, 2018[28]

The monthly distribution of Lyme disease claim lines in 2018 was different in rural and urban areas (figure 6). From May to September, rural areas had a greater share of Lyme disease claim lines than urban areas, but the reverse was true from October to April. The location where the patient received the service cited in the claim line may not be the same as the location where the infection was transmitted. Thus, some of the infections diagnosed in the fall months may result from urban residents "leaf peeping"—viewing fall foliage—in rural areas, then returning to their urban areas to be diagnosed.

[28] Due to rounding, the rural and urban bars for September and November appear to have the same value though they are of different heights. Rounded to the first decimal place, the rural value for September is 9.3 percent and the urban value 8.6 percent. For November, the rural value is 6.5 percent and the urban value is 7.4 percent.

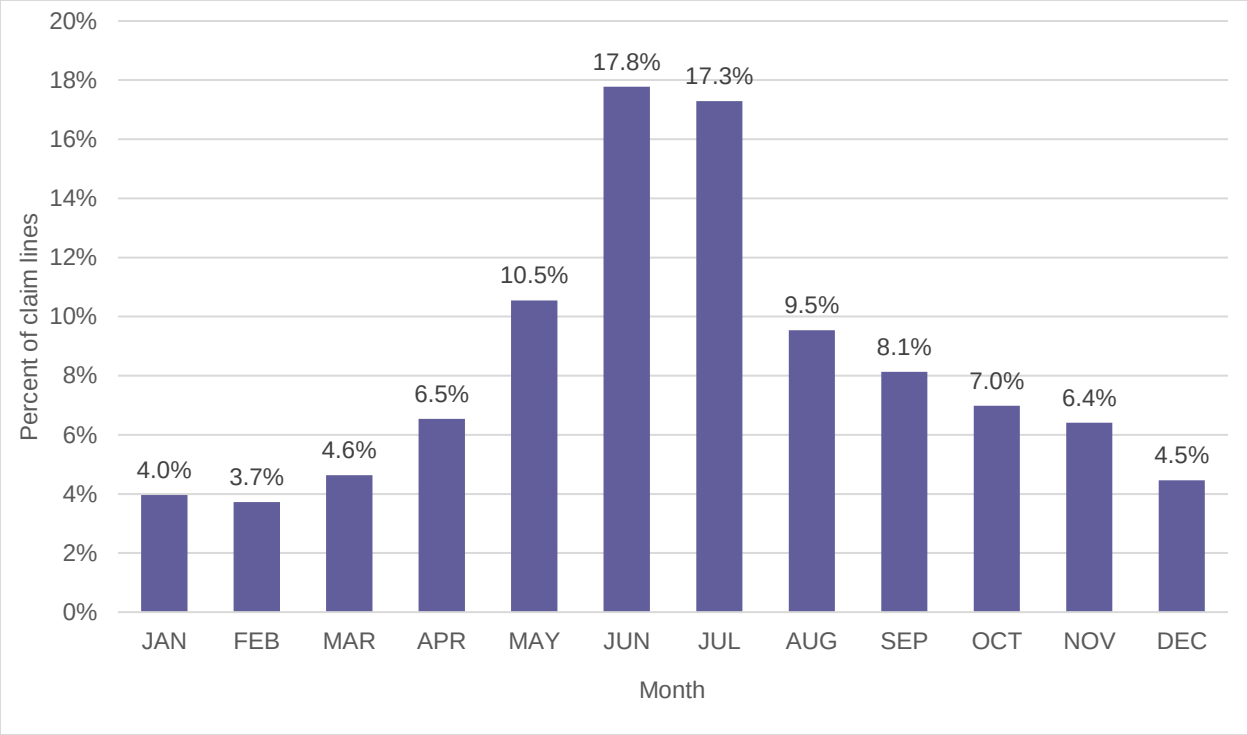


Figure 7. Monthly distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease, 2018

The monthly distribution of claim lines for other tick-borne diseases in 2018 (figure 7) resembles that of Lyme disease claim lines (figure 5) in having its peak in June and July. But the differential between those and the surrounding months is even sharper. June represents 17.8 percent of the share of the other tick-borne disease claim line monthly distribution—7.3 percentage points more than May—and July represents 17.3 percent, 7.8 percentage points more than August. February (3.7 percent) and January (4.0 percent) were the months with the lowest share of other tick-borne disease claim lines.

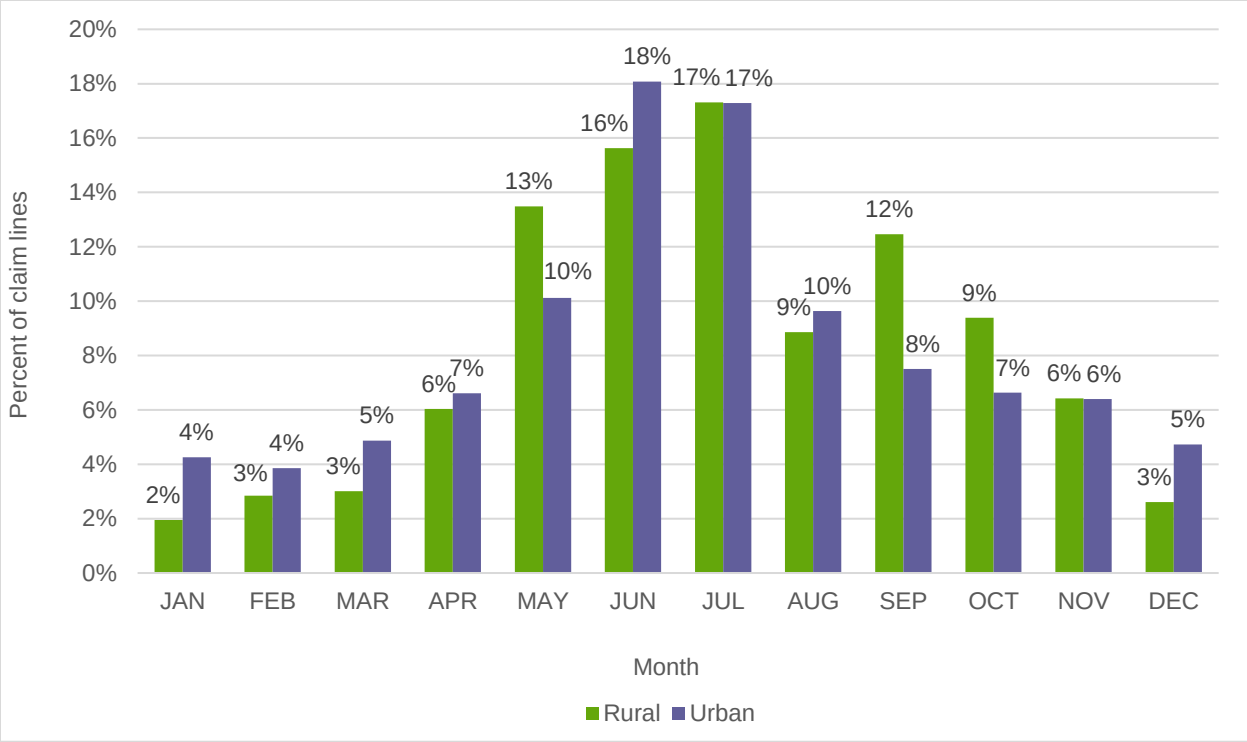


Figure 8. Monthly distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease by rural and urban areas, 2018

Rural and urban areas differed in their share of the 2018 monthly distribution of claim lines for tick-borne diseases other than Lyme (figure 8), just as they did for Lyme disease (figure 6). But the patterns of difference were distinct. In June, for example, urban areas had a larger share (18 percent) than rural areas (16 percent) of claim lines for other tick-borne diseases; and in July, rural and urban areas were nearly matched (both 17 percent). By comparison, rural areas surpassed urban areas in both months in their share of Lyme disease claim lines. But, in May and September, rural areas outstripped urban areas to a greater degree in the distribution of other tick-borne disease claim lines than in that of Lyme disease claim lines.

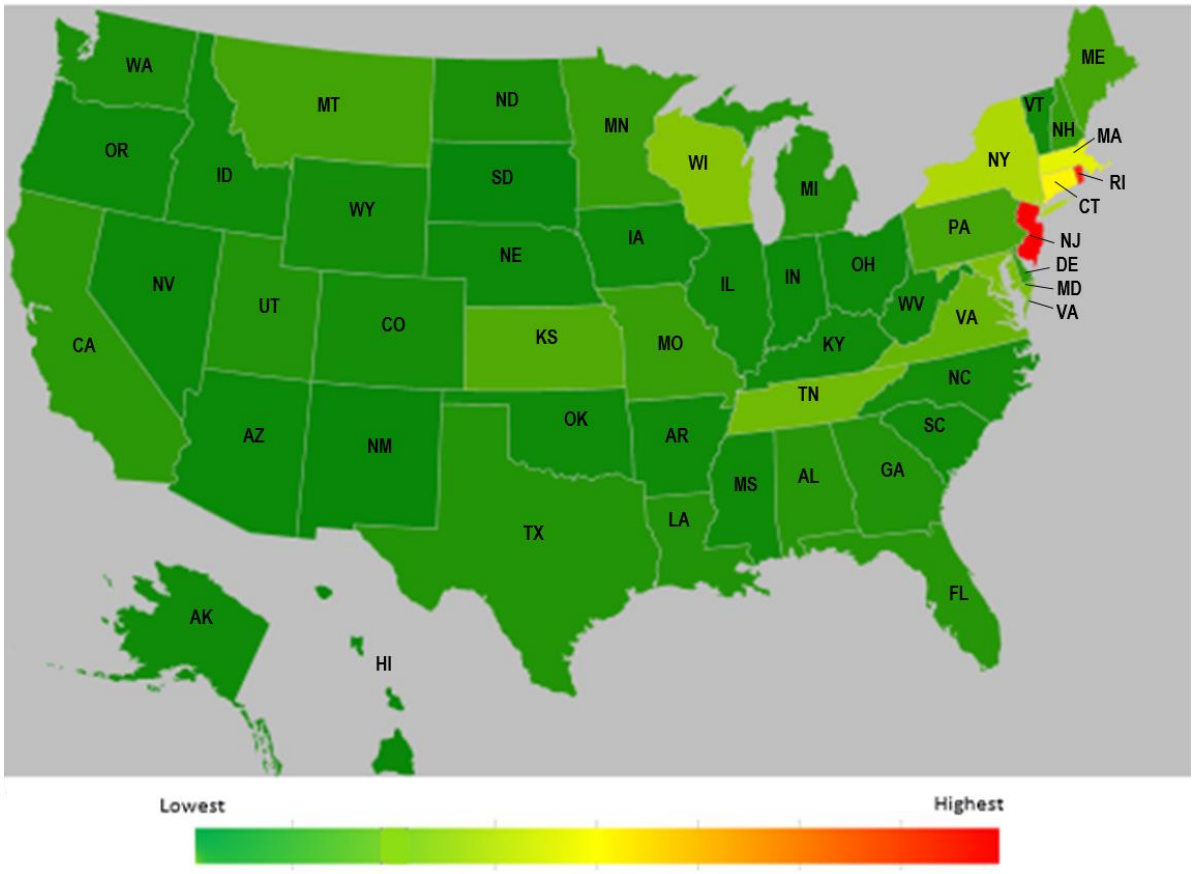


Figure 9. Claim lines with Lyme disease diagnoses as a percentage of all medical claim lines by state, 2007

State Distribution

In the heat maps in this section, states with a greater number of claim lines for a given diagnosis as a percentage of all medical claim lines by state fall toward the red end of the spectrum. In 2007, the five states that had the highest number of claim lines with Lyme disease diagnoses as a percentage of all medical claim lines by state were, from highest to lowest, New Jersey, Rhode Island, Connecticut, Massachusetts and New York (figure 9). All of these top five states were in the Northeast, a region historically associated with Lyme disease, and all were among the 16 locations that the CDC listed as having a high incidence of Lyme disease in 2017.[29] The bottom five states (from lowest to highest) in 2007—those with the lowest number of Lyme disease claim lines as a percentage of all medical claim lines—in the FAIR Health data were South Dakota, New Mexico, Hawaii, Arizona and Indiana.

[29] CDC, "Lyme Disease Maps: Most Recent Year," last reviewed December 21, 2018, https://www.cdc.gov/lyme/datasurveillance/maps-recent.html.

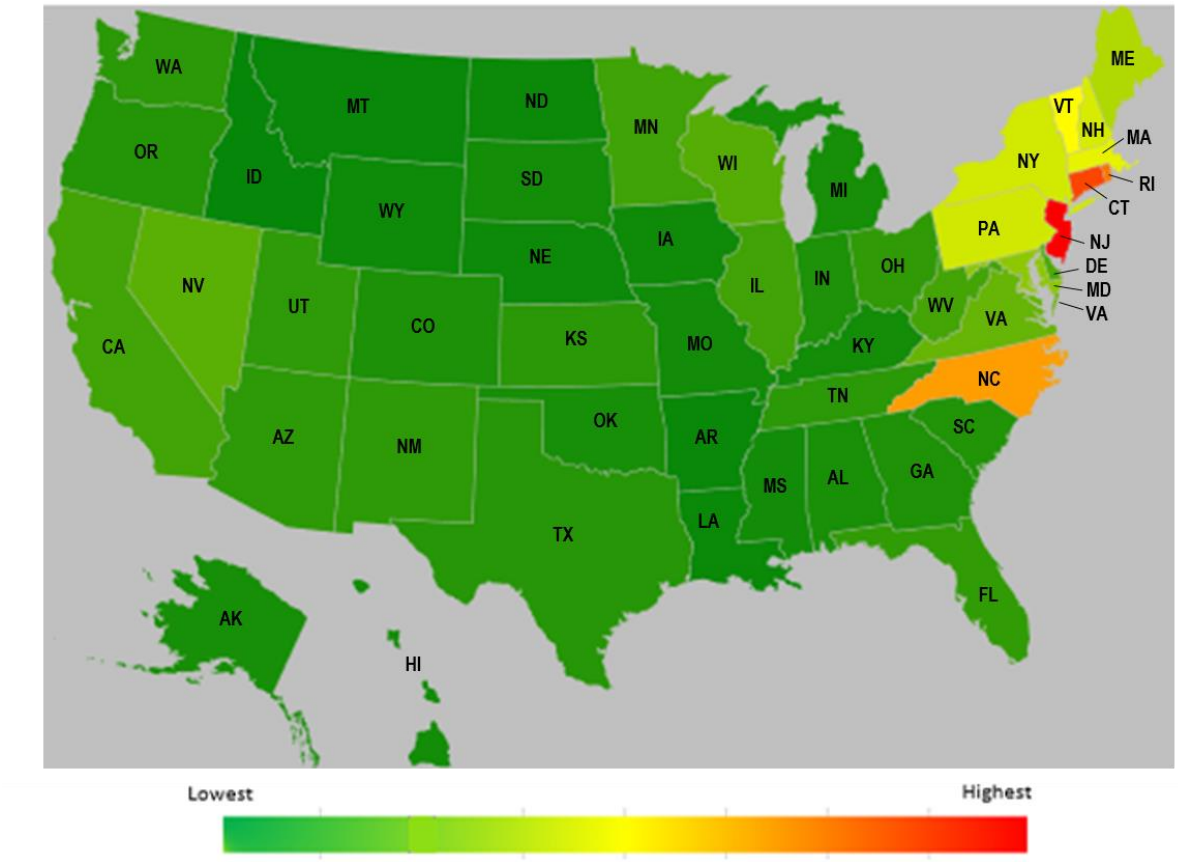


Figure 10. Claim lines with Lyme disease diagnoses as a percentage of all medical claim lines by state, 2018

In 2018, there were several changes to the top five states for Lyme disease claim lines (figure 10). New Jersey remained number one, with Connecticut now in second place and Rhode Island in third (a reversal of the latter two states' positions in 2007). Joining the top five were North Carolina (in fourth place) and Vermont (in fifth). Massachusetts and New York dropped out of the top 5 but remained in the top 10. Vermont, but not North Carolina, was included in the CDC's list of locations with high incidence of Lyme disease in 2017.[30] Whereas all the other states in FAIR Health's top five lists in 2007 and 2018 were in the Northeast, North Carolina represented the introduction of another region, the South.

The bottom five states for Lyme disease claim lines in 2018 were Indiana, Montana, Arizona, Louisiana and North Dakota. Indiana and Arizona had been in the bottom five in 2007 as well.

[30] CDC, "Lyme Disease Maps."

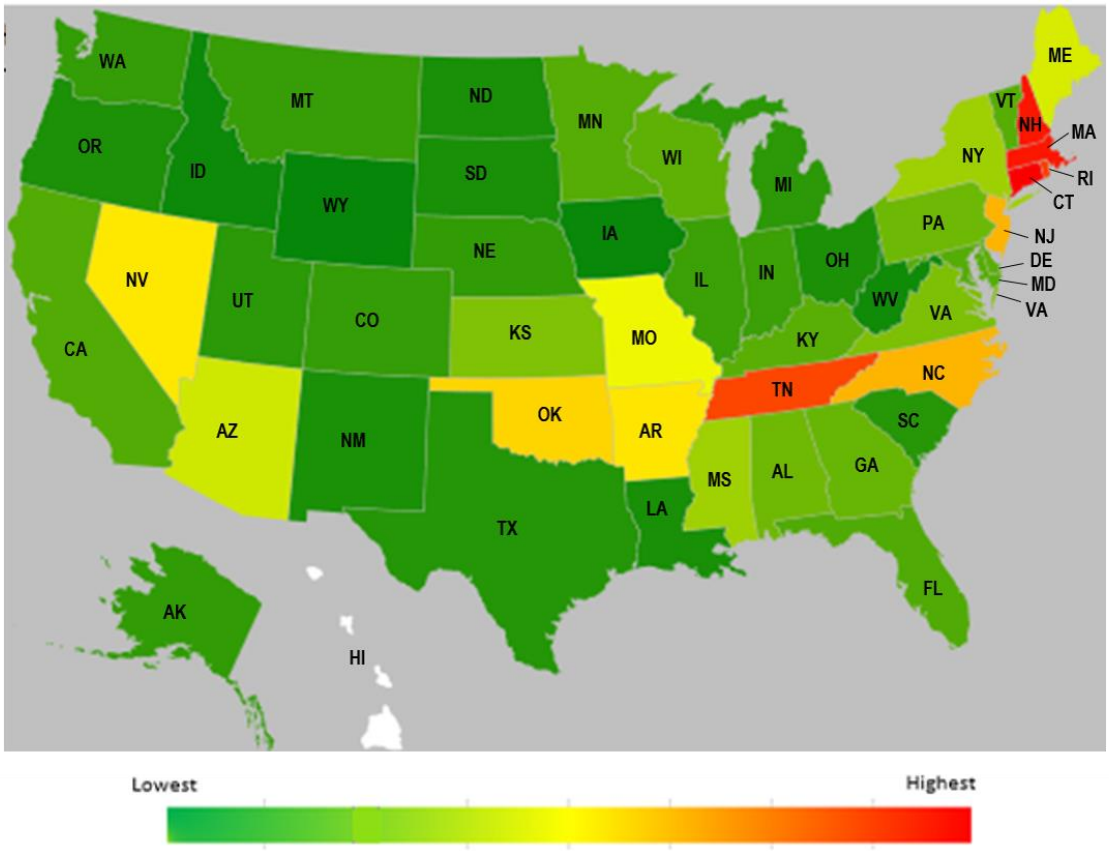


Figure 11. Claim lines with diagnoses of tick-borne diseases other than Lyme disease as a percentage of all medical claim lines by state, 2018[31]

Claim lines for tick-borne diseases other than Lyme disease were more widely distributed in 2018 than those for Lyme disease (figure 11). Nevertheless, all but one (Tennessee) of the top five states for other tick-borne diseases were in the Northeast; the top five were Connecticut, New Hampshire, Massachusetts, Rhode Island and Tennessee. The bottom five states for other tick-borne diseases were Wyoming, Iowa, Idaho, West Virginia and South Dakota.

[31] Hawaii had no claims data for tick-borne diseases other than Lyme disease.

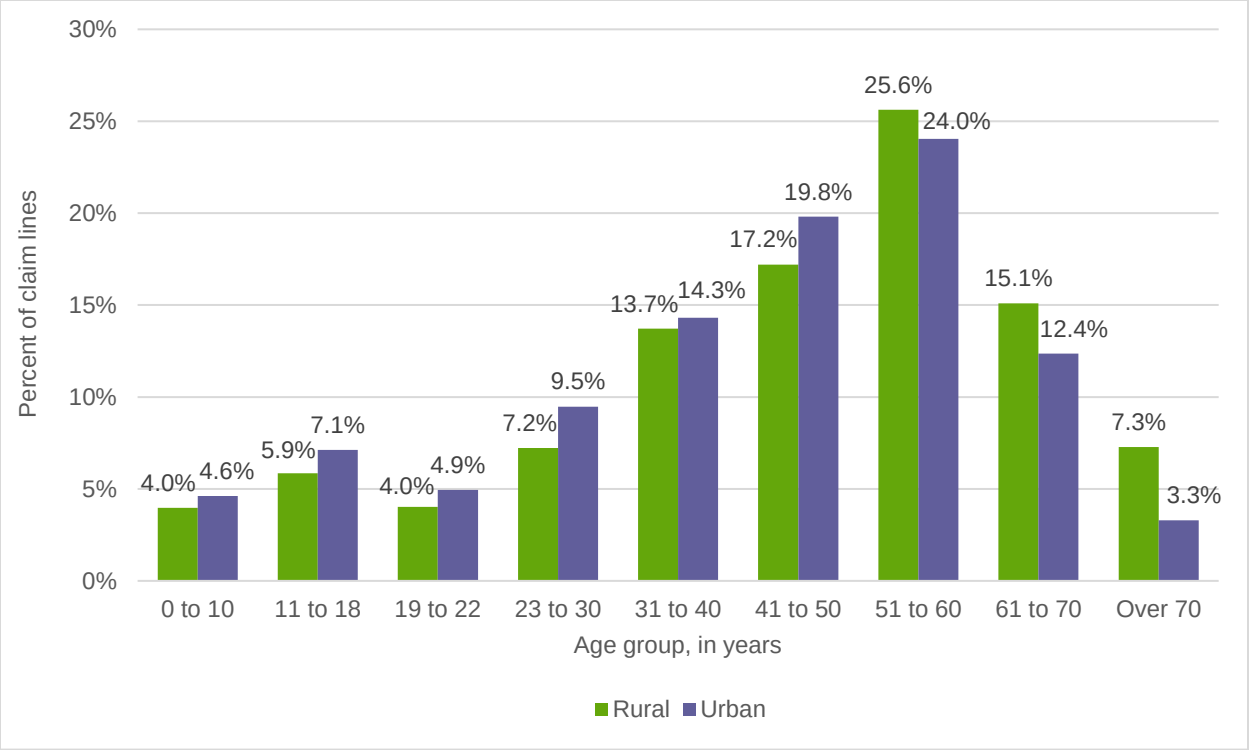


Figure 12. Distribution of claim lines with Lyme disease diagnoses by age group and rural or urban area, 2018

Age and Gender

In both rural and urban areas in 2018, the largest share of the age distribution of claim lines with Lyme disease diagnoses was held by individuals aged 51 to 60 (figure 12). This age group represented approximately one quarter of Lyme disease claim lines (25.6 percent in rural areas, 24.0 percent in urban areas).

The age group 41-50 held the second largest share of Lyme disease claim lines in both rural and urban areas. The third largest share differed in rural and urban areas. In rural areas, the third largest age group was that of individuals aged 61 to 70 (15.1 percent); in urban areas, it was individuals aged 31 to 40 (14.3 percent). The difference may be related to the larger share of older people in rural areas compared to urban areas.[32]

CDC age group statistics for 2017, which do not differentiate between rural and urban, show the age group with the highest number of probable and confirmed reported cases as 60-64, with the second highest number in the age group 55-59.[33]

[32] Amy Symens Smith and Edward Trevelyan, US Census Bureau, *The Older Population in Rural America: 2012-2016*, poster presented at the Annual Meeting of the Population Association of America, Austin, TX, April 10-13, 2019, https://www.census.gov/content/dam/Census/newsroom/press-kits/2019/paa/paa-poster-older-population.pdf.
[33] CDC, "Lyme Disease Charts and Figures: Most Recent Year," last reviewed December 21, 2018, https://www.cdc.gov/lyme/datasurveillance/charts-figures-recent.html.

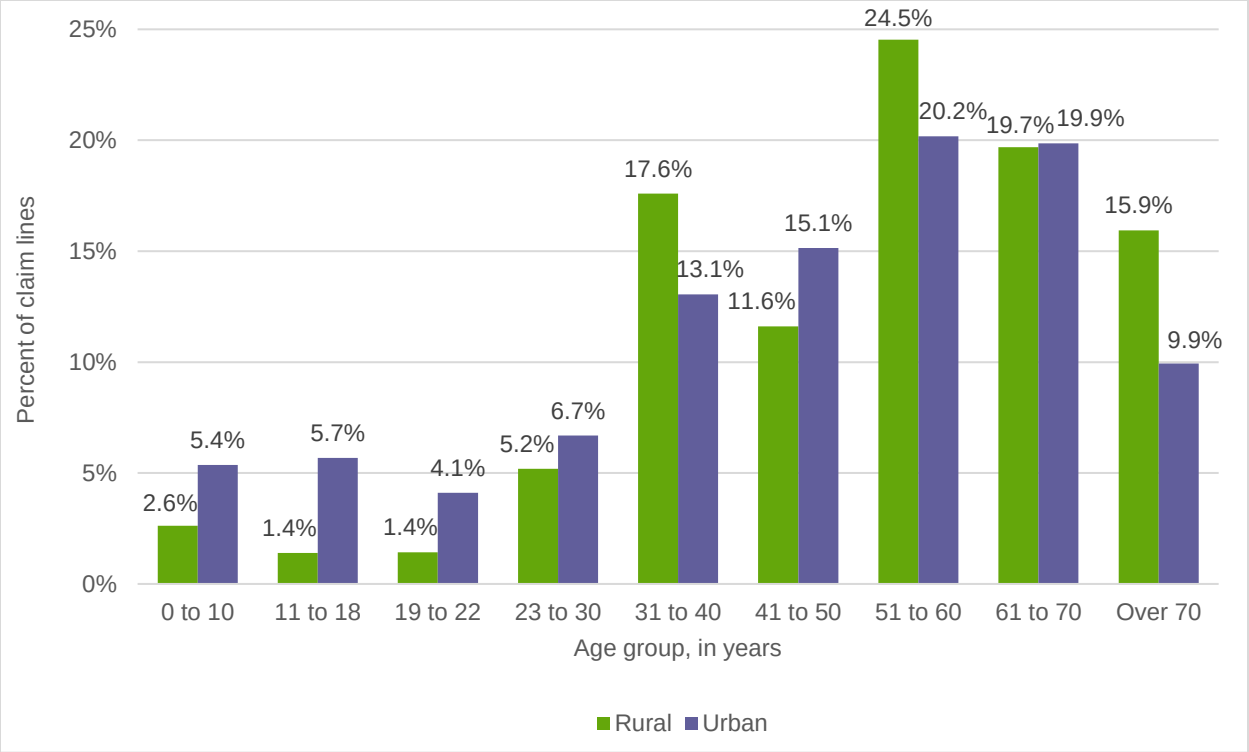


Figure 13. Distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease by age group and rural or urban area, 2018

As with Lyme disease, in both rural and urban areas in 2018, the largest share of the age distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease was held by the age group 51 to 60 (figure 13). That distinction was more marked in rural areas, where the age group 51-60 constituted 24.5 percent of the distribution. In urban areas, that same age group accounted for only 20.2 percent of the distribution, just slightly more than the 19.9 percent share held by individuals aged 61 to 70 in urban areas. In rural areas, the 61-70 age group also came in second, with a 19.7 percent share.

The third largest share in rural areas was held by the age group 31-40 (17.6 percent), and in urban areas by the age group 41-50 (15.1 percent).

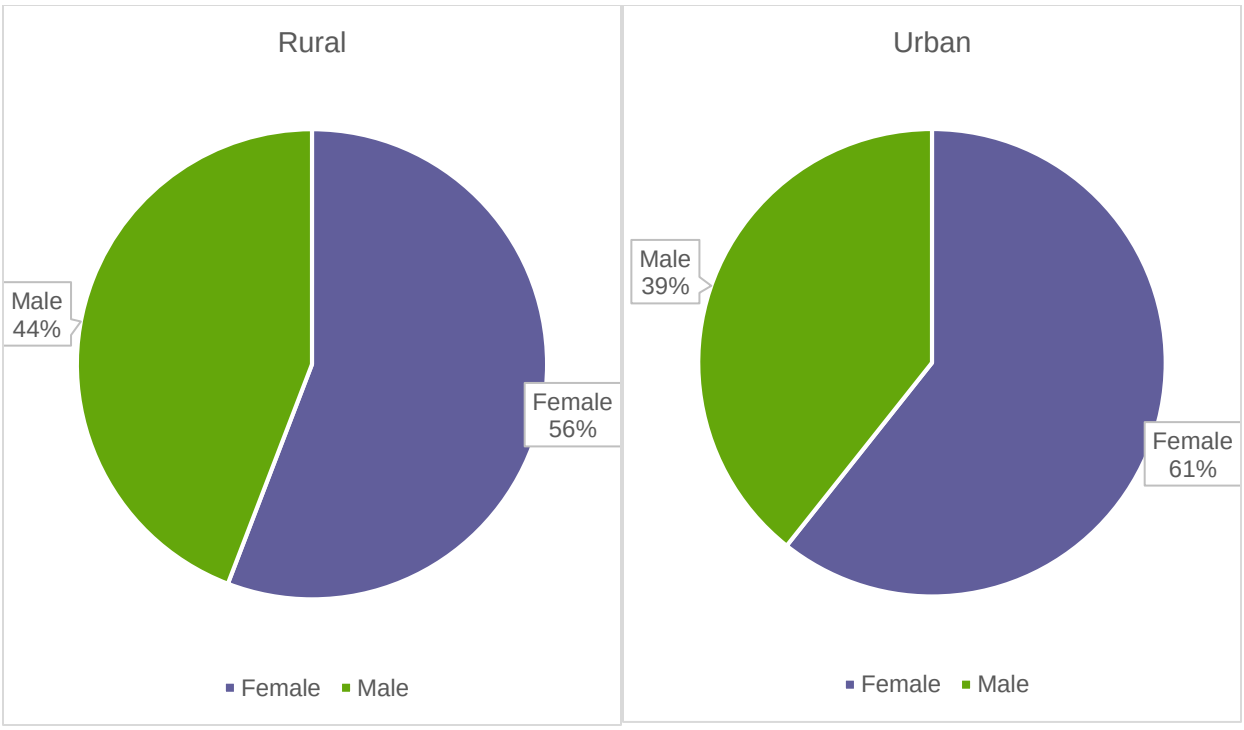


Figure 14. Distribution of claim lines with Lyme disease diagnoses by gender in rural (left) and urban (right) areas, 2018

In rural and urban areas in 2018, more claim lines with Lyme disease diagnoses were submitted for females than males (figure 14). The difference was slightly greater in urban than rural areas. In urban areas, the percentage of claim lines for females (61 percent) was 1.6 times as great as that for males (39 percent), while in rural areas the percentage of claim lines for females (56 percent) was 1.3 times as great as that for males (44 percent).

According to CDC data for 2017, among patients with reported confirmed and probable cases of Lyme disease, males predominated over females by 58 percent to 42 percent—nearly the opposite of FAIR Health findings.[34] FAIR Health data are based on clinical diagnoses, while the CDC surveillance case definition of Lyme disease relies primarily on laboratory evidence of infection.[35] Some researchers have suggested that female patients diagnosed with Lyme disease may be less likely than males to test positive for infection.[36,37] That may help explain why the gender distribution observed in the FAIR Health data differs from that in the CDC data.

[34] CDC, "Lyme Disease Charts and Figures: Most Recent Year."
[35] CDC, "Lyme Disease (*Borrelia burgdorferi*) 2017 Case Definition," https://wwwn.cdc.gov/nndss/conditions/lyme-disease/case-definition/2017/.
[36] Alison W. Rebman et al., "Characteristics of Seroconversion and Implications for Diagnosis of Post-Treatment Lyme Disease Syndrome: Acute and Convalescent Serology among a Prospective Cohort of Early Lyme Disease Patients," *Clinical Rheumatology* 34, no. 3 (March 2015): 585-89, https://doi.org/10.1007%2Fs10067-014-2706-z.
[37] Alison Schwarzwalder et al., "Sex Differences in the Clinical and Serologic Presentation of Early Lyme Disease: Results from a Retrospective Review," *Gender Medicine* 7, no. 4 (2010): 320-29, https://doi.org/10.1016/j.genm.2010.08.002.

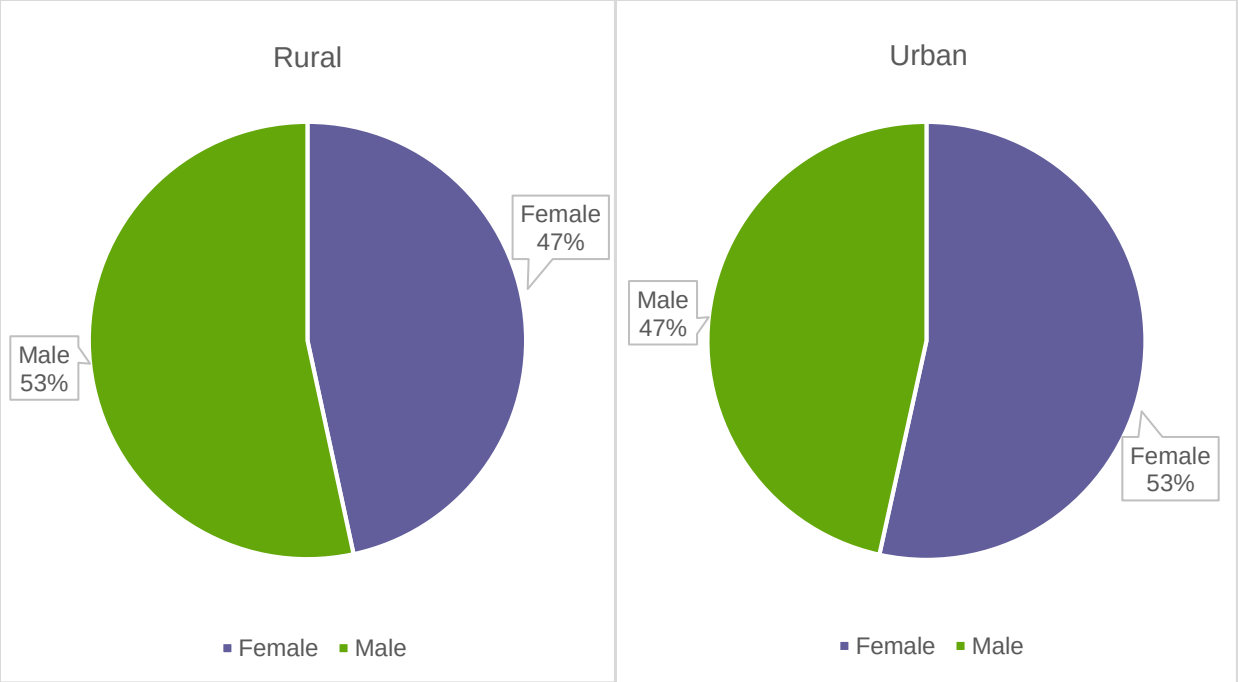


Figure 15. Distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease by gender in rural (left) and urban (right) areas, 2018

The gender distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease in 2018 in the FAIR Health repository varied in rural and urban areas (figure 15). In rural areas, more claim lines were submitted for males (53 percent) than females (47 percent); in urban areas, the reverse was true (47 percent for males, 53 percent for females).

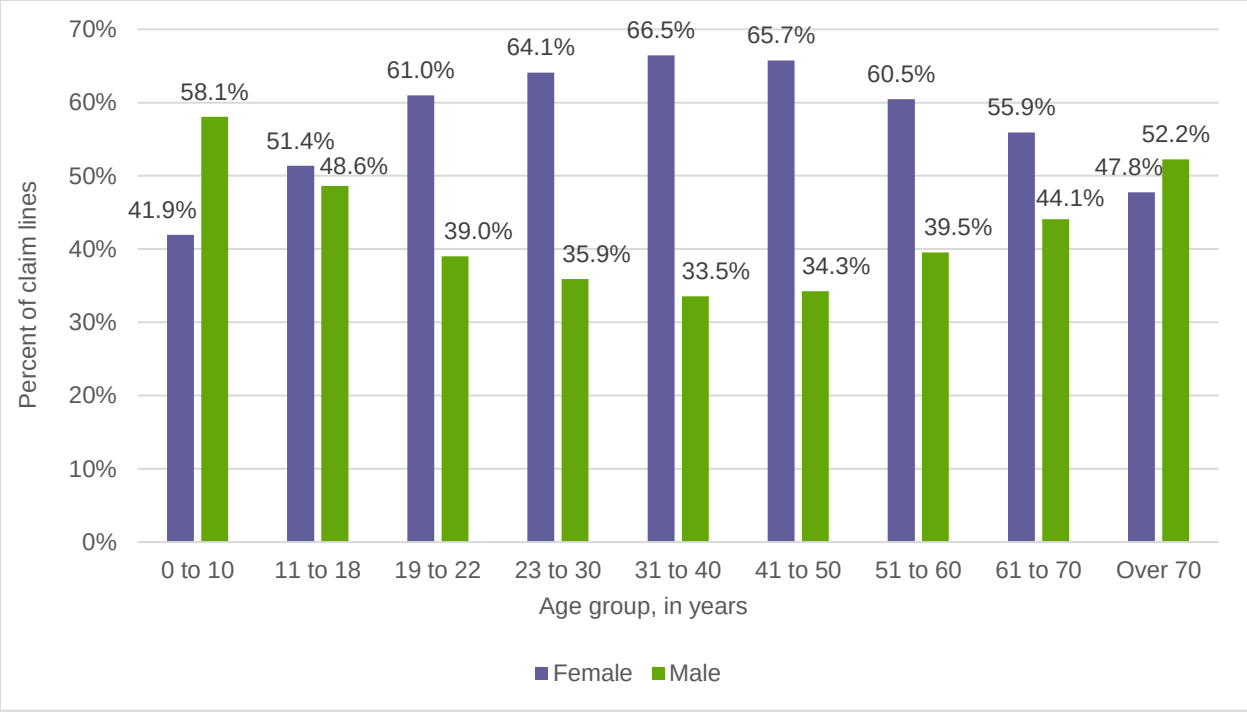


Figure 16. Distribution of claim lines with Lyme disease diagnoses by age group and gender, 2018

In 2018, more claim lines for Lyme disease were submitted for females than males in every age group from 11 to 70 (figure 16). Indeed, in the age range 23-50, claim lines for females were nearly double those for males. Claim lines for males predominated over those for females only in the youngest and oldest segments: the age groups 0-10 and over 70.

According to a CDC age and sex analysis, from 2001 to 2017, there were more confirmed cases of Lyme disease in males than females in every age group from 0 to 74; females predominated only in the age range 75 and older.[38] Again, the disparity between CDC and FAIR Health results may be explained, in part, by the use of confirmed cases in the CDC data versus clinical diagnoses in the FAIR Health claims data. In addition, the FAIR Health findings were for 2018, while the CDC findings were for 2001 to 2017.

[38] CDC, "Lyme Disease Charts and Figures: Historical Data."

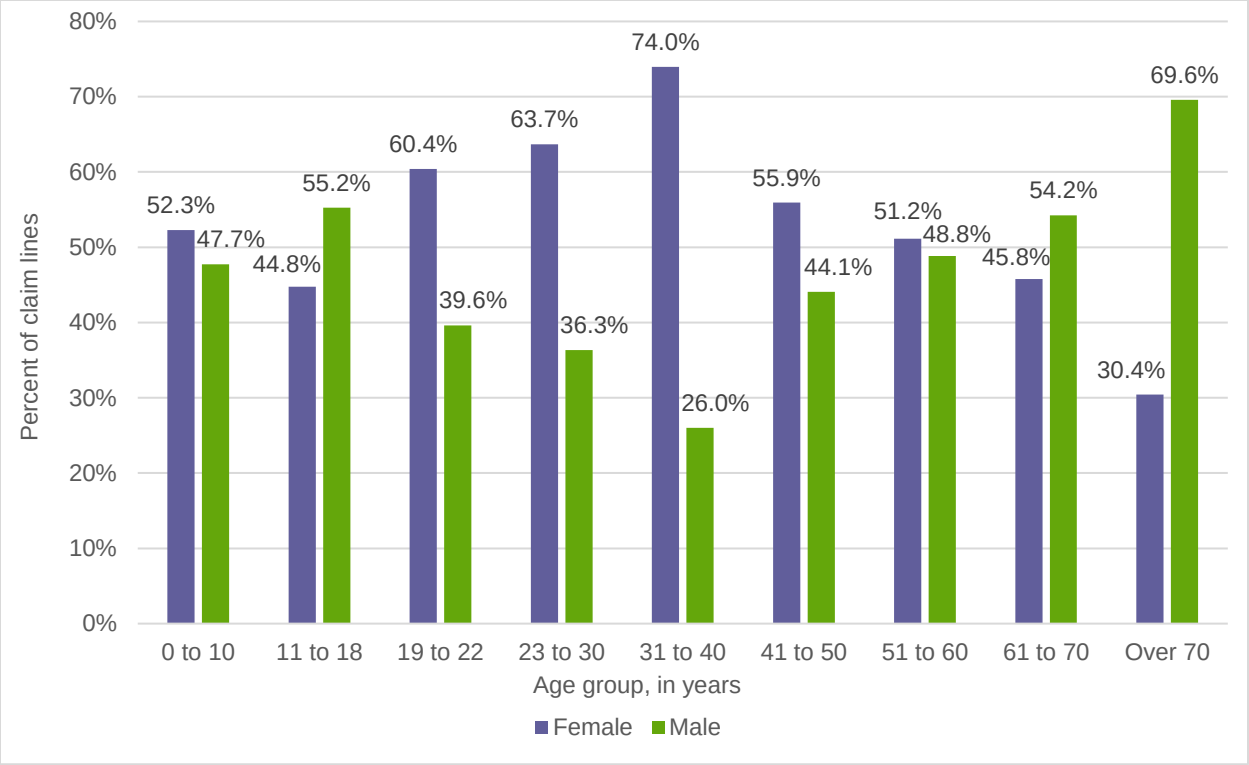


Figure 17. Distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease by age group and gender, 2018

The age and gender distribution was more varied in claim lines with diagnoses of tick-borne diseases other than Lyme disease in 2018 in the FAIR Health repository (figure 17). In three age groups—11-18, 61-70 and over 70—more claim lines were submitted for males than females. In the rest, claim lines for females predominated, but the size of the gender gap differed widely. Claim lines for males and females were nearly equal in the age group 51-60, but the female share was nearly three times as great as the male share among individuals aged 31 to 40.

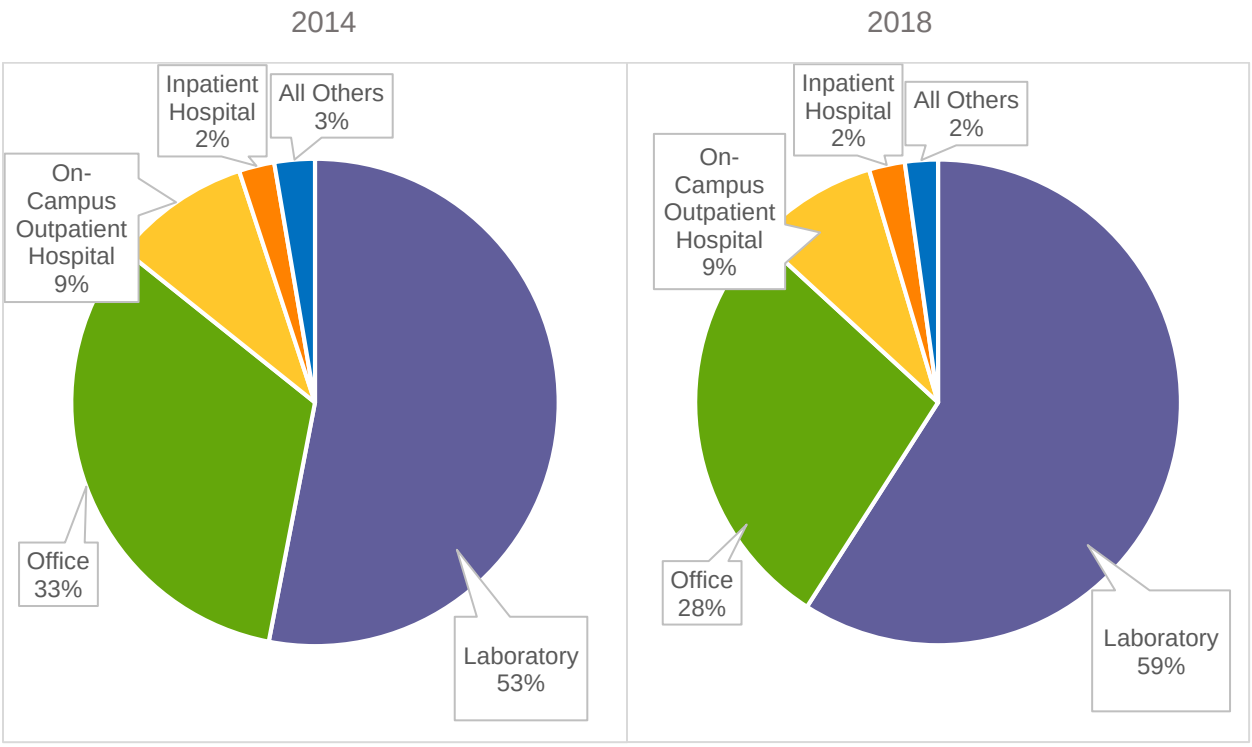


Figure 18. Distribution of claim lines with Lyme disease diagnoses by place of service, 2014 (left) and 2018 (right)

Places of Service

The distribution of claim lines by place of service where individuals received care for Lyme disease did not change greatly from 2014 to 2018 (figure 18). The laboratory accounted for the largest share of claim lines both years, with the share growing from 53 percent in 2014 to 59 percent in 2018. This is to be expected since laboratory testing is recommended for diagnosing Lyme disease.[39] The office held the second largest share both years, probably because Lyme disease is often treated by a primary care physician.[40]

[39] CDC, "Lyme Disease—Diagnosis and Testing," last reviewed August 15, 2019, https://www.cdc.gov/lyme/diagnosistesting/index.html.
[40] American Lyme Disease Foundation, Inc., "How to Find a Physician to Treat Lyme Disease," last updated November 13, 2019, https://www.aldf.com/finding-a-physician/.

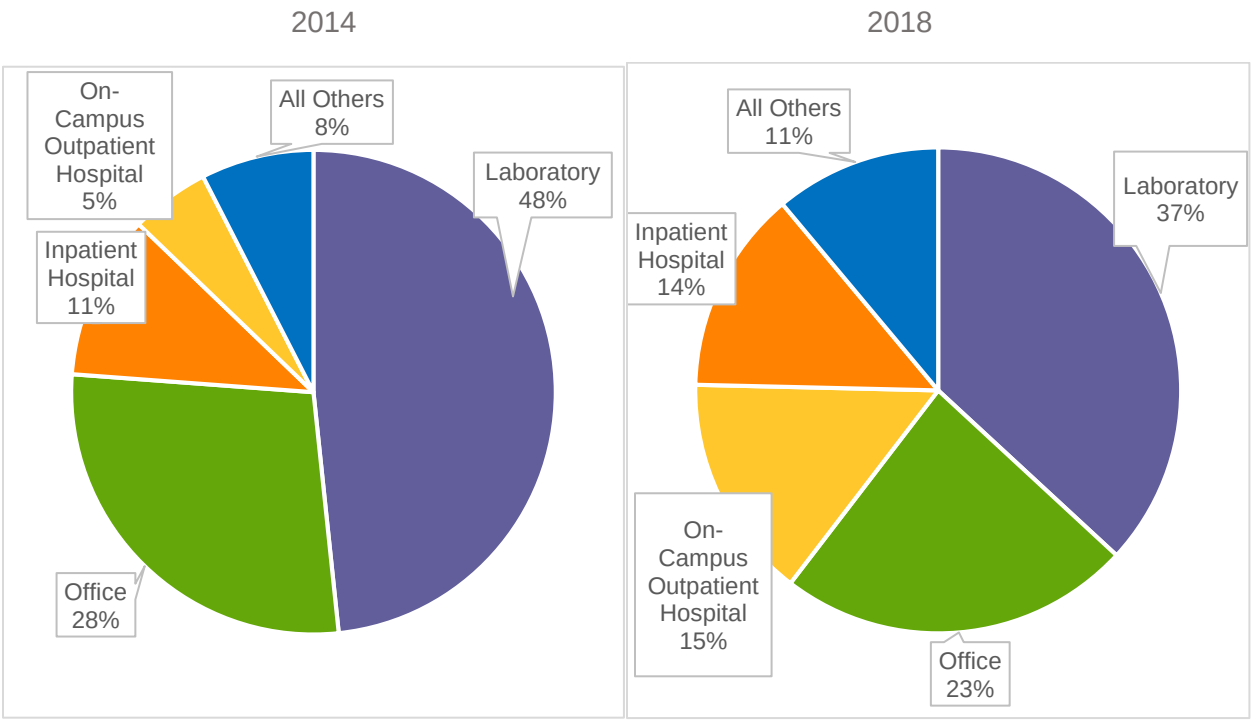
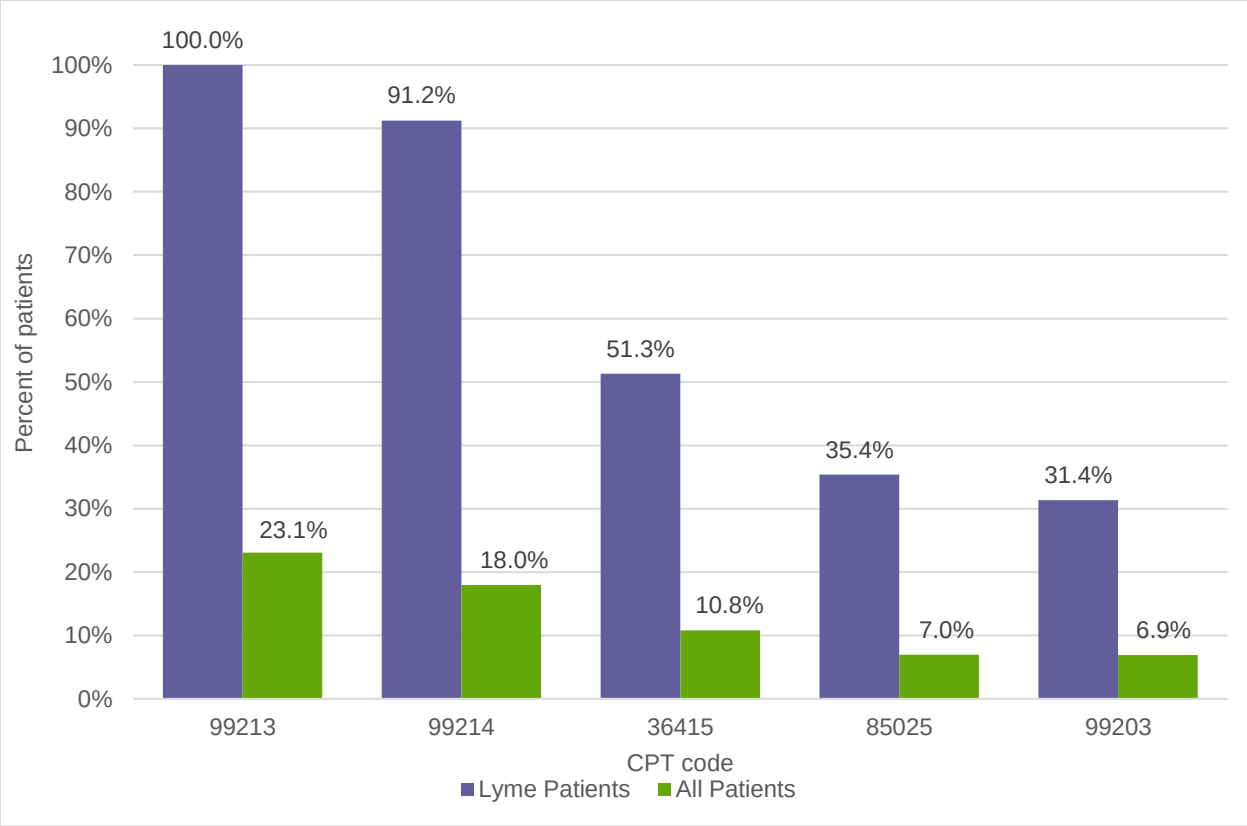


Figure 19. Distribution of claim lines with diagnoses of tick-borne diseases other than Lyme disease by place of service, 2014 (left) and 2018 (right)

For tick-borne diseases other than Lyme disease, the distribution of claim lines by place of service (figure 19) underwent greater change from 2014 to 2018 than for Lyme disease (figure 18). The laboratory share of the other tick-borne diseases distribution fell from 48 percent in 2014 to 37 percent in 2018, and the office share declined from 28 percent to 23 percent. The share held by the on-campus outpatient hospital grew from 5 percent to 15 percent, and the inpatient hospital share increased from 11 percent to 14 percent. By comparison, for Lyme disease, the on-campus outpatient hospital and inpatient hospital shares remained constant both years (at, respectively, nine percent and two percent). One factor in the difference between the distributions is that some other tick-borne diseases may be more likely than Lyme disease to be severe enough to require hospitalization.[41]

[41] American Lyme Disease Foundation, Inc., "How to Find a Physician to Treat Lyme Disease."



CPT Code	Description
99213	Established patient office or other outpatient visit, typically 15 minutes
99214	Established patient office or other outpatient visit, typically 25 minutes
36415	Insertion of needle into vein for collection of blood sample
85025	Complete blood cell count (red blood cells, white blood cells, platelets), automated test
99203	New patient office or other outpatient visit, typically 30 minutes

Figure 20. Five most common procedures by percent of patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

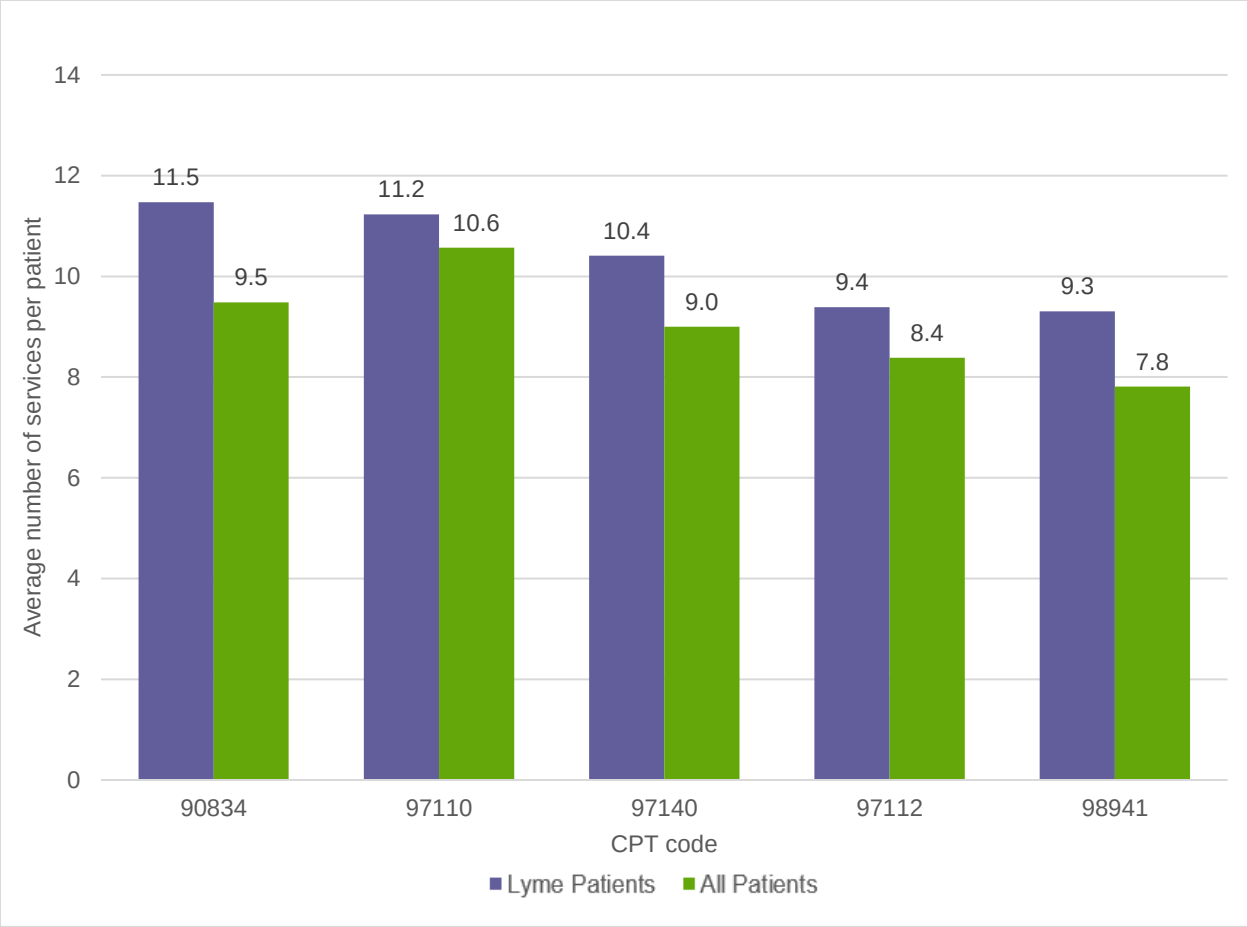
Procedures

By percent of patients, the most common procedure performed for patients with a Lyme disease diagnosis (Lyme patients) in 2018 was a 15-minute office or other outpatient visit for an established patient (CPT 99213; figure 20). This service was rendered to 100 percent of Lyme patients. By comparison, it was rendered to only 23.1 percent of all patients (including patients with and without Lyme disease diagnoses). This may be because many patients in the total population do not receive office visits in a given year or because they receive care using other codes.

The second most common procedure by percent of patients was another office visit: a 25-minute office or other outpatient visit for an established patient (CPT 99214). Of Lyme patients, 91.2 percent had this service rendered, compared to 18.0 percent of all patients.

The third most common procedure was insertion of a needle into a vein for collection of blood sample (CPT 36415). Since blood testing is recommended for Lyme diagnoses, it is not surprising that this blood draw would be performed for 51.3 percent of Lyme patients, but only 10.8 percent of all patients.

The fourth most common procedure was a complete blood cell count, automated test (CPT 85025) and the fifth a 30-minute office or other outpatient visit for a new patient (CPT 99203). Both were performed for a greater percentage of Lyme patients than all patients.



CPT Code	Description
90834	Psychotherapy, 45 minutes with patient and/or family member
97110	Therapeutic exercise to develop strength, endurance, range of motion and flexibility, each 15 minutes
97140	Manual (physical) therapy techniques to 1 or more regions, each 15 minutes
97112	Therapeutic procedure to reeducate brain-to-nerve-to-muscle function, each 15 minutes
98941	Chiropractic manipulative treatment, 3 to 4 spinal regions

Figure 21. Five most common procedures by volume in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Figure 21 shows the five most common procedures by volume (total number of claim lines), rather than by percent of patients, that were performed for Lyme patients versus all patients in 2018. They are arrayed by the average number of times each procedure was performed on a patient in the Lyme patient population. Of these five procedures, the procedure performed the most times per Lyme patient was a 45-minute psychotherapy session with a patient and/or family member (CPT 90834). This service was rendered an average of 11.5 times per Lyme patient receiving the service, compared to 9.5 times per patient receiving the service in the all-patient population.

The rest of the five most common procedure codes by volume are either physical therapy codes (CPT 97110, 97140 and 97112) or a chiropractic procedure code (CPT 98941). Each procedure was performed, on average, more often for Lyme patients receiving the procedure than for individuals in the all-patient population receiving it.

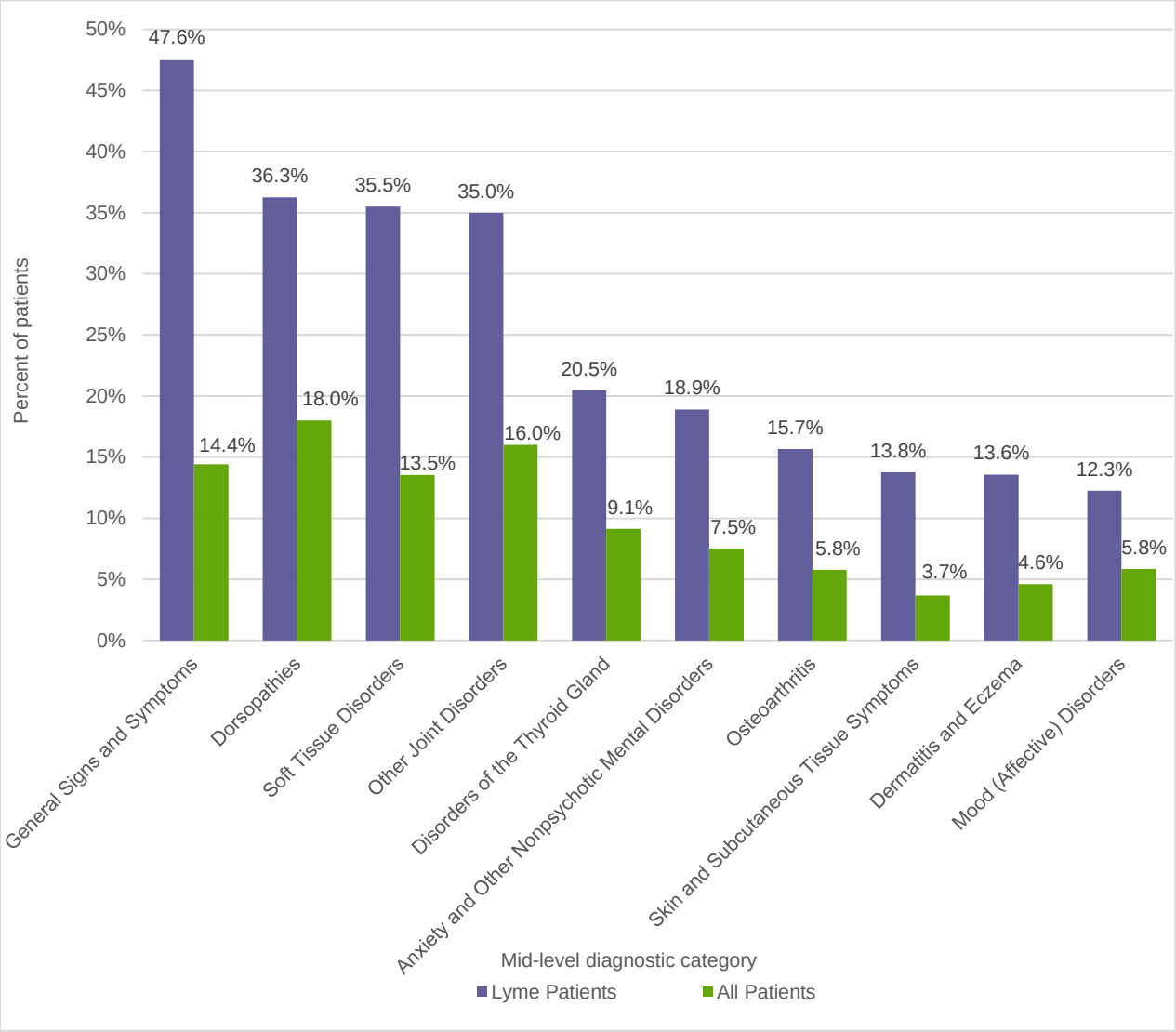


Figure 22. Ten most common other diagnoses by mid-level diagnostic category in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Other Diagnoses

Patients who have been diagnosed with Lyme disease often have other diagnoses. In 2018, the 10 most common “other diagnoses” found in Lyme patients after the initial diagnosis of Lyme disease, by mid-level diagnostic category, are shown in figure 22. (Mid-level diagnostic categories are more detailed than

higher diagnostic levels but less detailed than granular ones). The percentage of Lyme patients with the other diagnosis is compared to the percentage of all patients with that diagnosis.

The most common other diagnosis was general signs and symptoms (e.g., malaise and fatigue), which was more than three times as common in Lyme patients as in all patients. The second to fourth most common were, respectively, dorsopathies (disorders of the spine), soft tissue disorders (e.g., rheumatism) and other joint disorders (e.g., bursitis, general joint pain). All were from 2 to 2.5 times as likely to occur in Lyme patients as in all patients.

Diagnoses of disorders of the thyroid gland (the fifth most common other diagnosis) and anxiety and other nonpsychotic mental disorders (the sixth most common) were about 2.5 times as prevalent in Lyme patients as in all patients. The seventh to tenth most common other diagnoses were, respectively, osteoarthritis, skin and subcutaneous tissue symptoms, dermatitis and eczema, and mood (affective) disorders. Osteoarthritis was nearly three times as likely in Lyme patients as in all patients, skin and subcutaneous tissue symptoms nearly four times as likely, dermatitis and eczema nearly three times as likely, and mood (affective) disorders about twice as likely.

Many of these types of diagnoses—such as the malaise and fatigue component of general signs and symptoms, as well as soft tissue and joint disorders—have been linked in the past to either Lyme disease or to post-treatment Lyme disease syndrome (PTLDS), or both.[42,43] Because there is no diagnosis code for PTLDS or, as it is sometimes called, chronic Lyme disease, this analysis tracks patients diagnosed with Lyme disease but does not ascertain whether any have been characterized as having PTLDS or chronic Lyme disease.

[42] Columbia University Irving Medical Center, Lyme and Tick-Borne Diseases Research Center, "Signs and Symptoms," https://www.columbia-lyme.org/signs-and-symptoms.
[43] Alison W. Rebman et al., "The Clinical, Symptom, and Quality-of-Life Characterization of a Well-Defined Group of Patients with Posttreatment Lyme Disease Syndrome," *Frontiers in Medicine* (December 14, 2017), https://doi.org/10.3389/fmed.2017.00224.

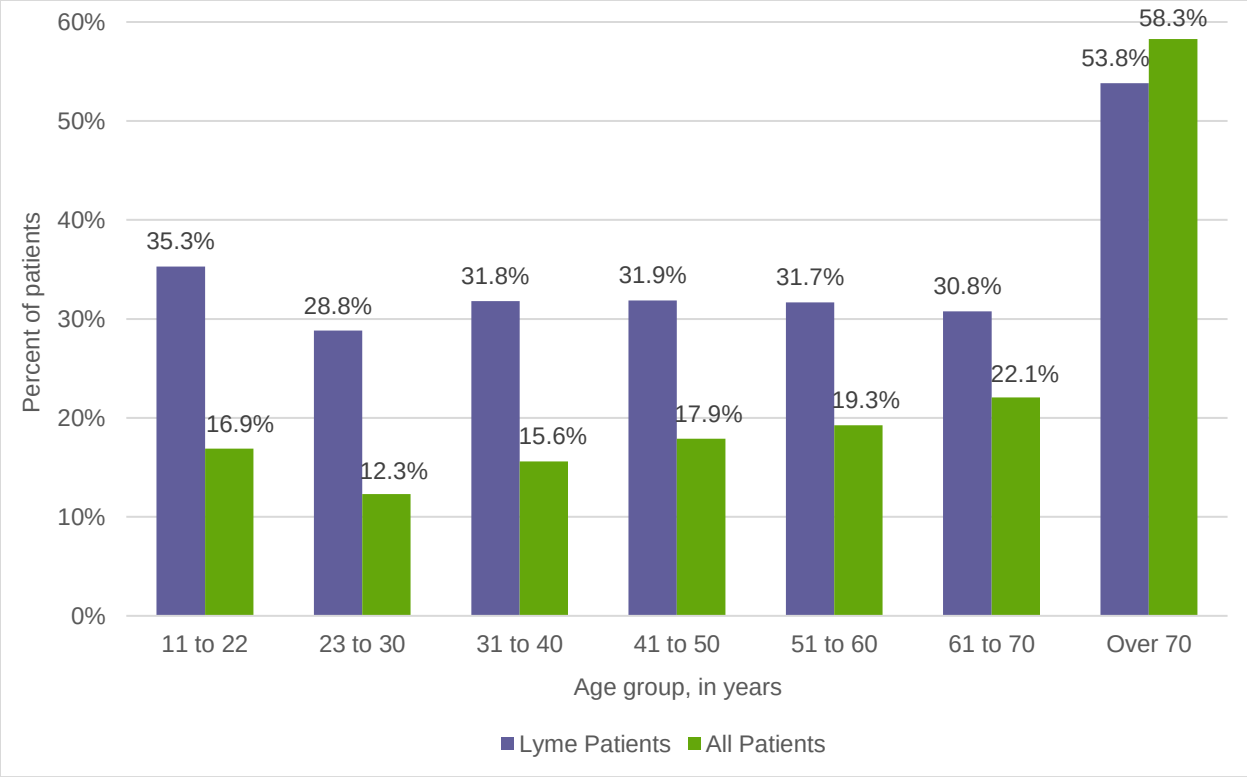


Figure 23. Diagnoses of general signs and symptoms, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Diagnoses of general signs and symptoms were more common in Lyme patients than in all patients in every age group from 11 to 70 in 2018 (figure 23). Only in the age group 70 and over were diagnoses of general signs and symptoms slightly more common in all patients than in Lyme patients (58.3 percent in all patients, 53.8 percent in Lyme patients). Statistically significant data were lacking for patients aged 0 to 10.

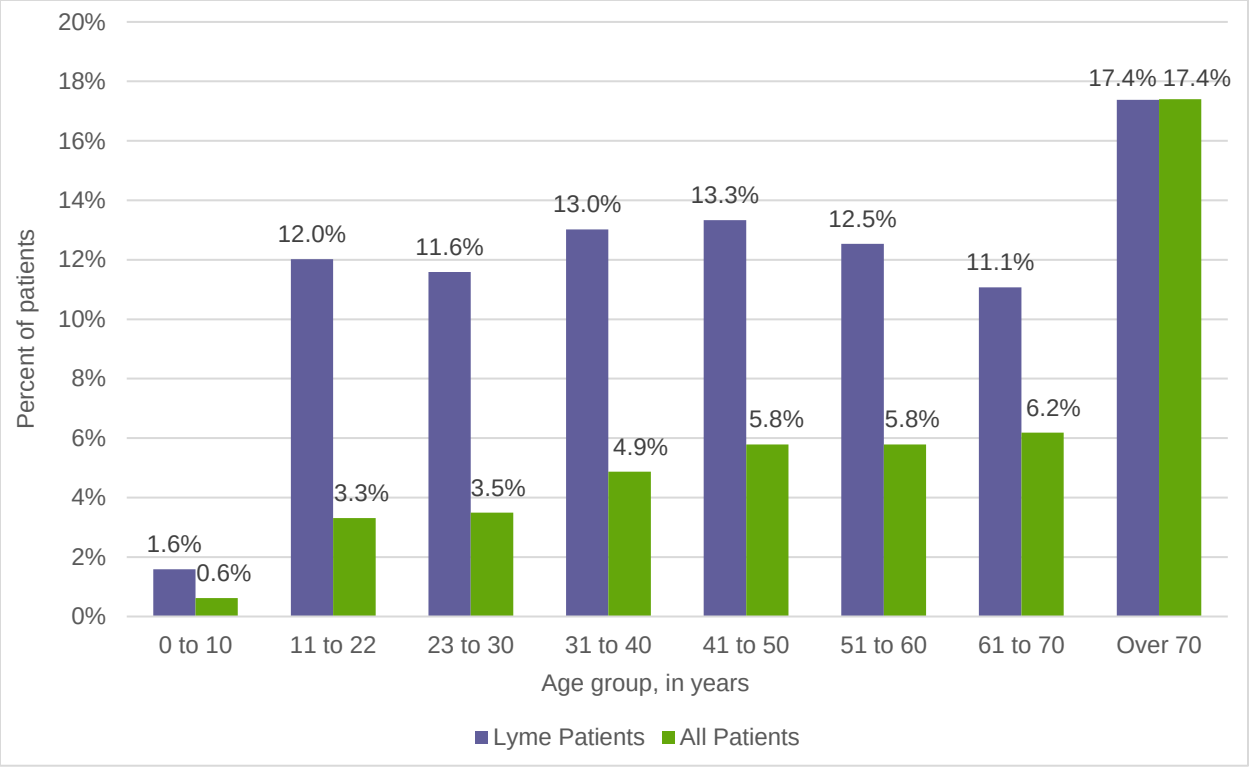


Figure 24. Diagnoses of malaise and fatigue, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Within the mid-level category of general signs and symptoms, an important granular category for Lyme disease is malaise and fatigue. This diagnosis was more prevalent in Lyme patients than in all patients in every age group from 0 to 70 in 2018; only in individuals over 70 was the share about the same in both patient cohorts (figure 24). The disparity was greatest in the age group 11 to 22, in which the share of Lyme patients diagnosed with malaise and fatigue was 12.0 percent, nearly four times as large as the share of all patients with that diagnosis (3.3 percent). In the age groups from 23 to 70, Lyme patients were about two to three times as likely as all patients to have malaise and fatigue.

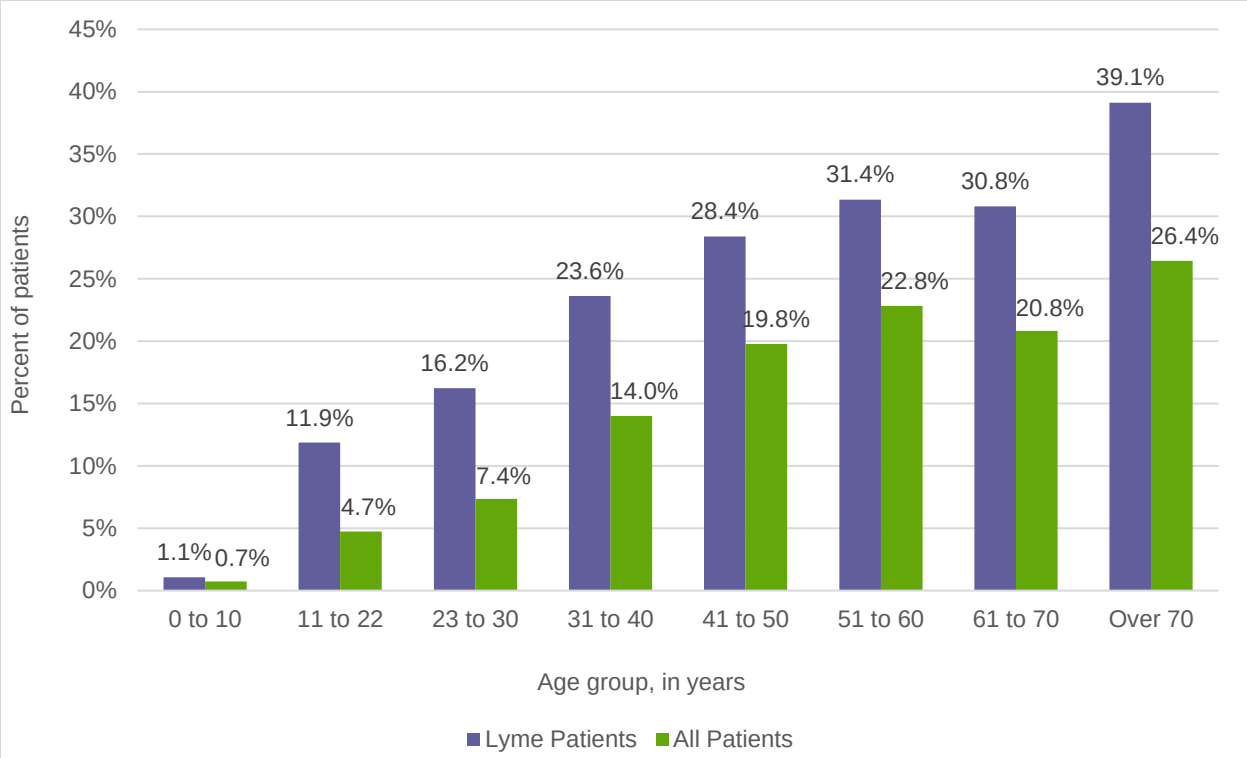


Figure 25. Diagnoses of dorsopathies, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Diagnoses of dorsopathies, which include conditions such as spondylopathies and cervical disc disorders and other spinal disc disorders, were more prevalent in every age group in the Lyme patient population than in the total patient population in 2018 (figure 25). Depending on the age group, the Lyme patient share of dorsopathy diagnoses ranged from almost 1.5 to 2.5 times as great as the all-patient population share.

Previous studies have reported back pain in cases of Lyme disease,[44] and have noted that back pain is particularly common in neuroborreliosis, a late stage of Lyme disease involving the central nervous system.[45]

[44] Sayed E. Wahezi and Steven A. Sparr, "Poster 249: Lyme Disease Presenting as Radicular Low Back Pain: A Case Report," *Archives of Physical Medicine and Rehabilitation* 89, no. 11 (November 2008): e100-e101, https://doi.org/10.1016/j.apmr.2008.09.249.
[45] Philipp Schwenkenbecher et al., "Common and Uncommon Neurological Manifestations of Neuroborreliosis Leading to Hospitalization," *BMC Infectious Diseases* 17, article no. 90 (January 21, 2017), https://doi.org/10.1186/s12879-016-2112-z.

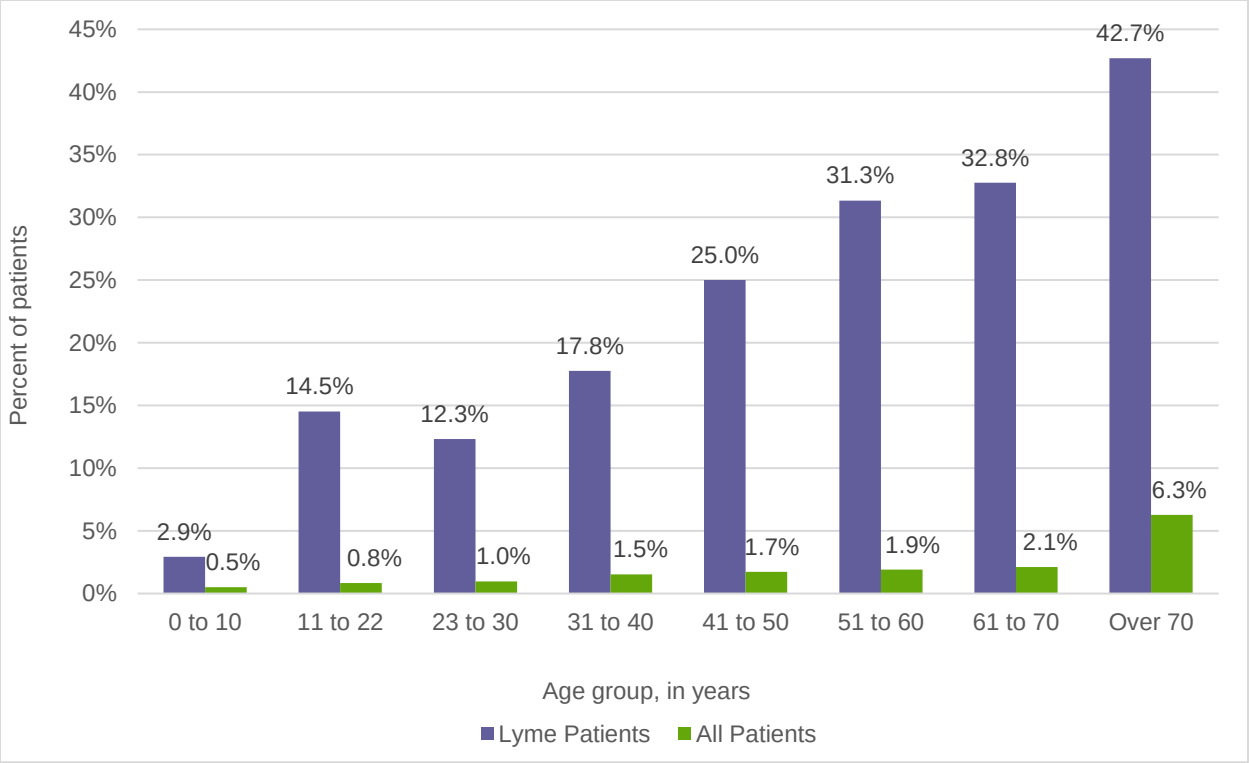


Figure 26. Diagnoses of soft tissue disorders, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Like dorsopathies, soft tissue disorders, which include diagnoses such as unspecified rheumatism, myalgia and neuralgia, were diagnosed more often in every age group in the Lyme patient population than in the total patient population in 2018 (figure 26). The disparity between the patient populations was even more pronounced than with dorsopathies. For the age range from 11 to 70, soft tissue disorder diagnoses were more than 10 times as common in Lyme patients as in all patients. In the age group 11 to 22—a group normally unlikely to develop soft tissue disorders—Lyme patients were 18 times as likely as those in the all-patient cohort to be diagnosed with such disorders.

Pain in soft tissues, such as muscles and tendons, has long been noted as a characteristic feature of Lyme disease.[46]

[46] Allen C. Steere, "Musculoskeletal manifestations of Lyme disease," *American Journal of Medicine* 98, no. 4, suppl. 1 (April 24, 1995): 44S-51S, https://www.amjmed.com/article/S0002-9343(99)80043-6/pdf.

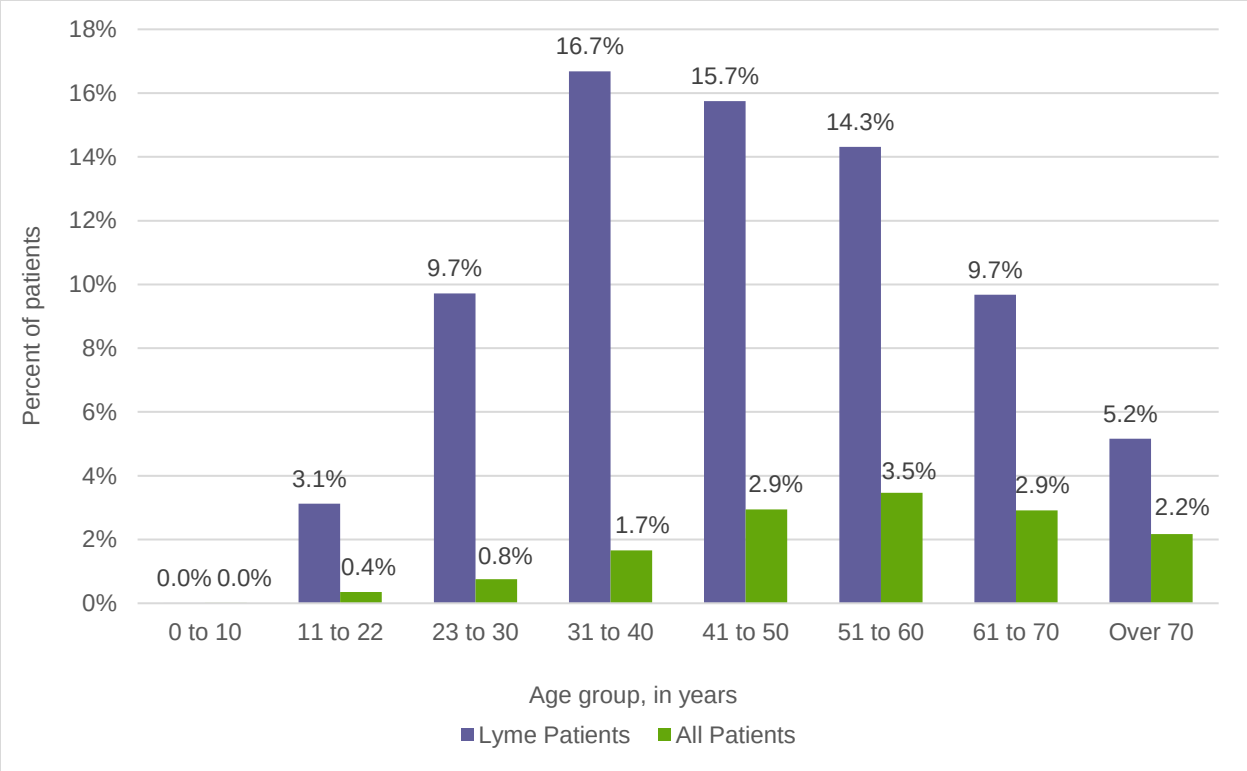


Figure 27. Diagnoses of fibromyalgia, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

One granular diagnosis classified under soft tissue disorders is fibromyalgia, a condition characterized by widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues. In 2018, diagnoses of fibromyalgia were more prevalent in the Lyme patient population than in the total patient population in every age group in the range from 11 to over 70 (figure 27). Depending on the age group within that range, the Lyme patient share of fibromyalgia diagnoses varied from about 2 to 12 times as great as the all-patient population share. Among Lyme patients, fibromyalgia diagnoses were most common in the 31-40 age group, in which 16.7 percent of Lyme patients were diagnosed with the condition compared to 1.7 percent of all patients.

Some studies have suggested an association between Lyme disease and fibromyalgia, though the connection is disputed.[47] Resemblance has been noted in the characteristics of PTLDS and fibromyalgia.[48]

[47] Gary P. Wormser et al., "Brief Report: Long-Term Assessment of Fibromyalgia in Patients with Culture-Confirmed Lyme Disease," *Arthritis & Rheumatology* 67, no. 3 (March 2015): 837-39, https://doi.org/10.1002/art.38972.
[48] Stéphanie Ranque-Garnier et al., "Management of Patients Presenting with Generalized Musculoskeletal Pain and a Suspicion of Lyme Disease," *Médecine et Maladies Infectieuses* 49, no. 2 (March 2019): 157-66, https://doi.org/10.1016/j.medmal.2019.01.008.

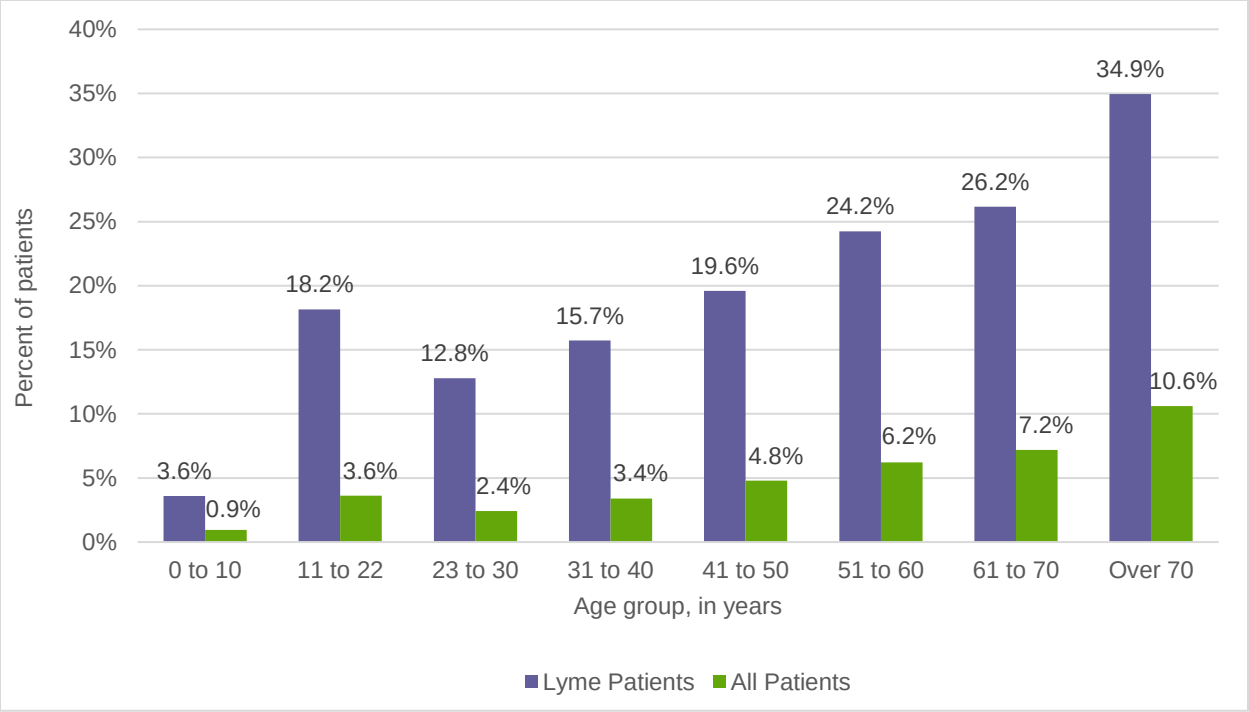


Figure 28. Diagnoses of "other joint disorder," by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

"Other joint disorder" (figure 28) is a subcategory of "other joint disorders" (figure 22) that includes joint stiffness, effusion of the joint and pain in the joints. Diagnoses of "other joint disorder" were more prevalent in the Lyme patient population than in the total patient population in every age group in 2018 (figure 28). Depending on the age group, "other joint disorder" diagnoses were about three to five times as common in Lyme patients as in all patients.

Joint swelling and pain have been found to occur frequently in patients with Lyme disease.[49] Lyme arthritis, marked by joint swelling and pain, has been described as the most common feature of late-stage Lyme disease.[50]

[49] Columbia University Irving Medical Center, Lyme and Tick-Borne Diseases Research Center, "Signs and Symptoms."
[50] Sheila L. Arvikar and Allen C. Steere, "Diagnosis and Treatment of Lyme Arthritis," *Infectious Disease Clinics of North America* 29, no. 2 (June 2015): 269-80, https://doi.org/10.1016/j.idc.2015.02.004.

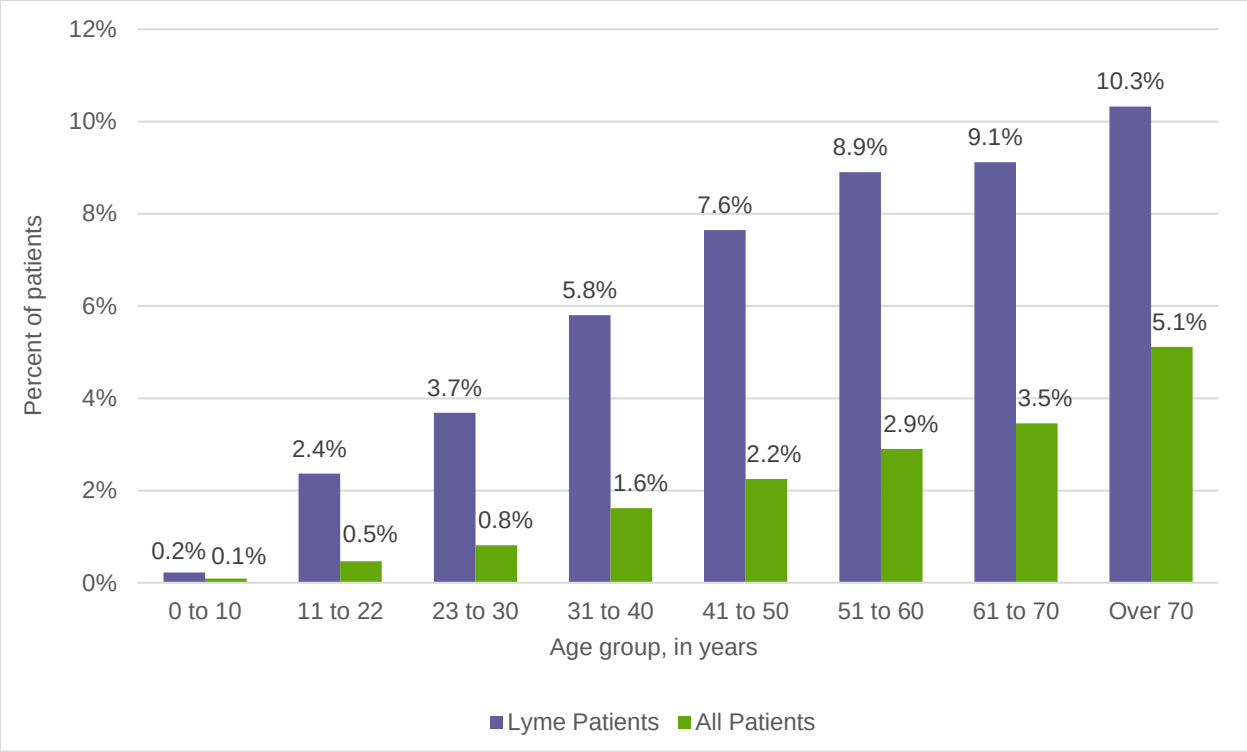


Figure 29. Diagnoses of thyroid disorders, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

"Thyroid disorders" (figure 29) is a subcategory of "disorders of the thyroid gland" (figure 22). Diagnoses of thyroid disorders—including autoimmune thyroiditis, such as Hashimoto's thyroiditis—were more prevalent in the Lyme patient population than in the total patient population in all age groups in 2018 (figure 29). In the age range 11 to 30, Lyme patients were about 4.5 times as likely to be diagnosed with thyroid disorders as all patients. Depending on the age group, Lyme patients 31 and older were from 2 to 3.5 times as likely to be diagnosed with thyroid disorders as individuals in the all-patient population.

Claims have been made for years of an association between Lyme disease and thyroid disorders such as Hashimoto's thyroiditis, though the link has not been scientifically established.[51,52]

[51] Natural Endocrine Solutions, "Is There a Connection between Lyme Disease and Thyroid Conditions?," November 12, 2012, https://www.naturalendocrinesolutions.com/articles/is-there-a-connection-between-lyme-disease-and-thyroid-disease/.
[52] Jenny Lelwica Buttacio, "An Introduction to Lyme Disease and Thyroid Health," ProHealth.com, July 24, 2017, https://www.prohealth.com/library/an-introduction-to-lyme-disease-and-thyroid-health-42601.

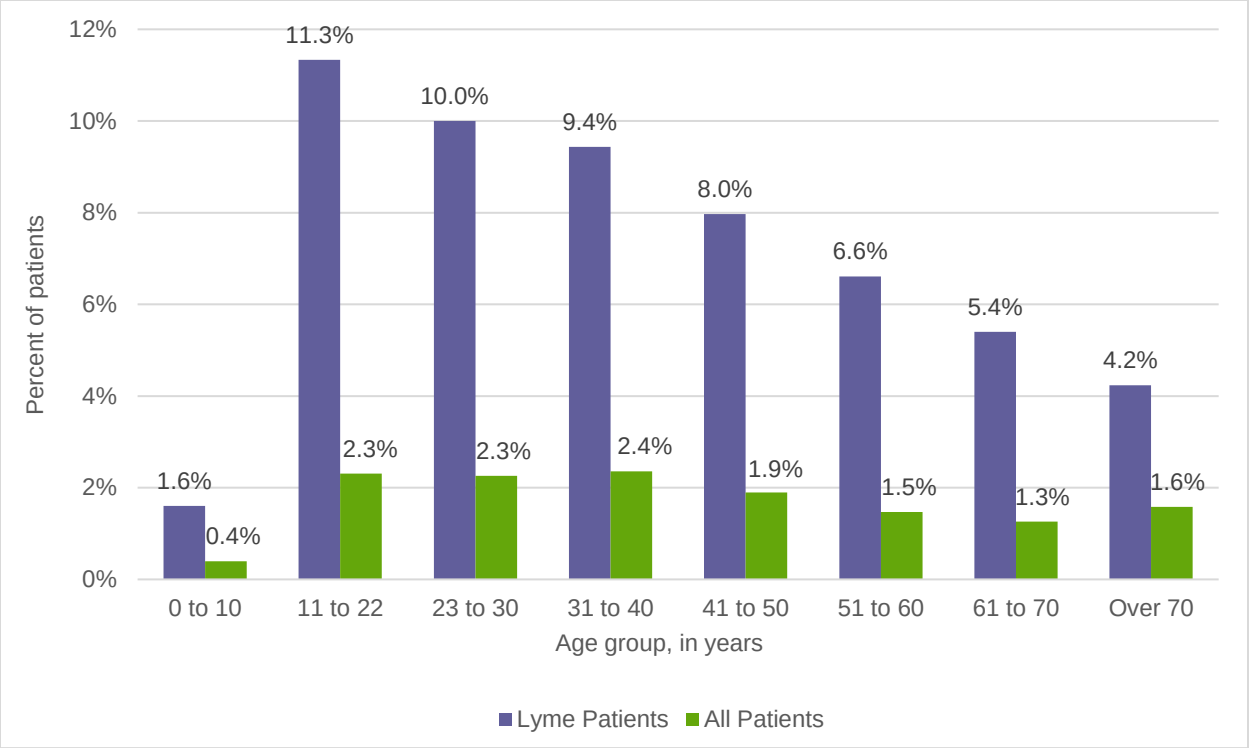


Figure 30. Diagnoses of anxiety disorders, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

In 2018, diagnoses of anxiety disorders were more common in every age group in the Lyme patient population than in the all-patient population (figure 30). Depending on the age group, individuals who had been diagnosed with Lyme disease were from 2.5 to 5 times as likely to be diagnosed with anxiety disorders as all patients.

Neuropsychiatric symptoms, including anxiety symptoms, have been regarded as common in Lyme disease.[53] Axis I psychiatric disorders, such as depressive and anxiety disorders, have been found to be more common in patients with chronic Lyme disease than in other patients.[54]

[53] Columbia University Irving Medical Center, Lyme and Tick-Borne Diseases Research Center, "Signs and Symptoms."
[54] Afton L. Hassett et al., "Role of Psychiatric Comorbidity in Chronic Lyme Disease," *Arthritis & Rheumatism (Arthritis Care & Research)* 59, no. 12 (December 15, 2008): 1742-49, https://doi.org/10.1002/art.24314.

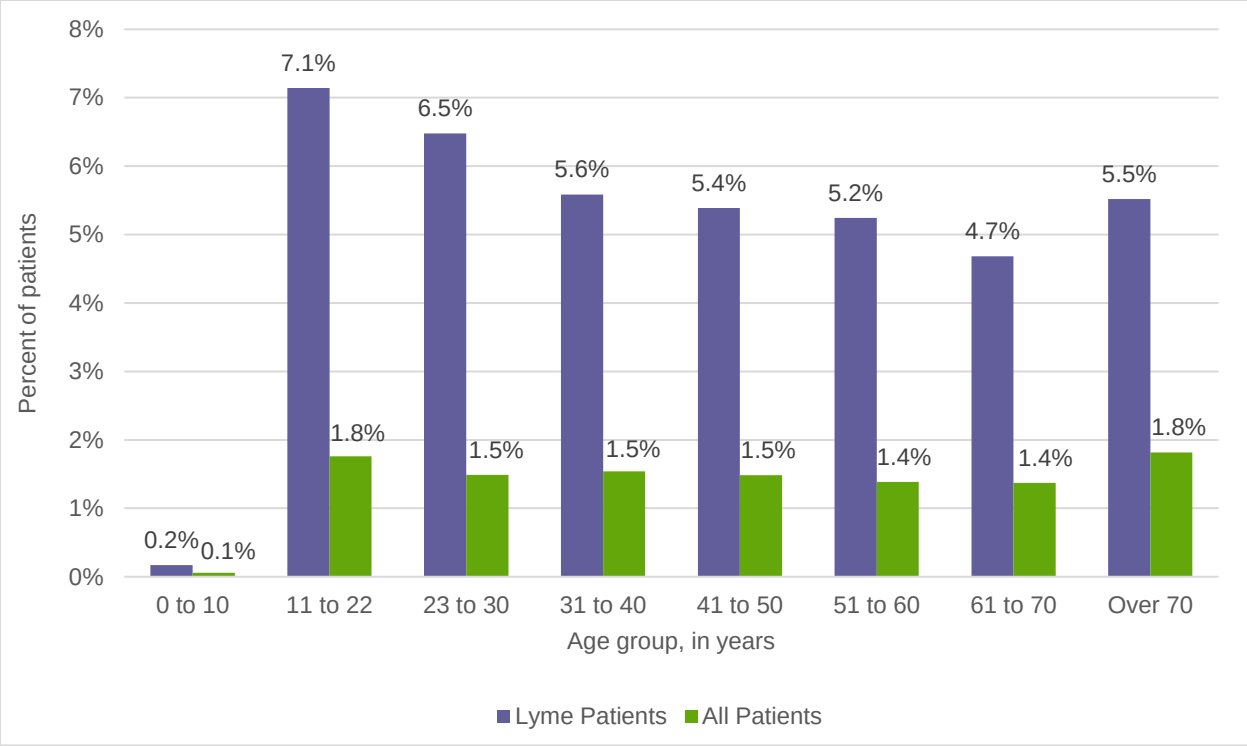


Figure 31. Diagnoses of major depressive disorder, by age group, in patients diagnosed with Lyme disease (Lyme patients) versus all patients, 2018

Diagnoses of major depressive disorder, which is classified under mood (affective) disorders, were more common in every age group in Lyme patients than in all patients in 2018 (figure 31). From age 11 to 70, Lyme patients were about 3.5 to 4 times as likely as patients in the total population to be diagnosed with the disorder, depending on the age group.

Depressed mood has been characterized as a typical mood symptom of Lyme disease.[55] Past research has especially linked depressive states with late or chronic Lyme disease.[56,57]

Conclusion

Lyme disease is the nation's predominant tick-borne disease, and it is growing. Claim lines for Lyme disease more than doubled as a percentage of all medical claim lines from 2007 to 2018, with the increase more prominent in urban than rural areas. Although Lyme disease is historically associated with the Northeast, North Carolina was one of the top five states in 2018 for Lyme disease claim lines as a percentage of all medical claim lines. The summer months are the peak season for Lyme disease, but claim lines with Lyme disease diagnoses were submitted year round in 2018. More claim lines with Lyme disease diagnoses were submitted for females than males in 2018. In that year, the largest share of Lyme disease claim lines was held by individuals aged 51 to 60. In 2014 and 2018, the laboratory and the office

[55] Columbia University Irving Medical Center, Lyme and Tick-Borne Diseases Research Center, "Signs and Symptoms."
[56] B. A. Fallon and J. A. Nields, "Lyme Disease: A Neuropsychiatric Illness," *American Journal of Psychiatry* 151, no. 11 (November 1994): 1571-83, https://doi.org/10.1176/ajp.151.11.1571.
[57] Hassett et al., "Role of Psychiatric Comorbidity in Chronic Lyme Disease."

were the places of service most often used for services associated with Lyme disease patients. In 2018, the 10 most common “other diagnoses” received by patients who had been diagnosed with Lyme disease were all received by a greater percentage of Lyme disease patients than of the total patient population. Among these were general signs and symptoms, dorsopathies, soft tissue disorders (including fibromyalgia) and other joint disorders. Also in the top 10 other diagnoses for Lyme disease patients were anxiety and other nonpsychotic mental disorders, as well as mood (affective) disorders.

Much still remains unknown about Lyme disease. FAIR Health conducted this study to help fill the gap in knowledge and to provide a foundation to advance the work of other researchers.

About FAIR Health

FAIR Health is a national, independent nonprofit organization dedicated to bringing transparency to healthcare costs and health insurance information through data products, consumer resources and health systems research support. FAIR Health qualifies as a public charity under section 501(c)(3) of the tax code. FAIR Health possesses the nation's largest collection of private healthcare claims data, which includes over 30 billion claim records contributed by payors and administrators who insure or process claims for private insurance plans covering more than 150 million individuals. FAIR Health licenses its privately billed data and data products—including benchmark modules, data visualizations, custom analytics and market indices—to commercial insurers and self-insurers, employers, providers, hospitals and healthcare systems, government agencies, researchers and others. Certified by the Centers for Medicare & Medicaid Services (CMS) as a national Qualified Entity, FAIR Health also receives data representing the experience of all individuals enrolled in traditional Medicare Parts A, B and D; FAIR Health houses data on Medicare Advantage enrollees in its private claims data repository. FAIR Health can produce insightful analytic reports and data products based on combined Medicare and commercial claims data for government, providers, payors and other authorized users. FAIR Health's free, award-winning, national consumer websites are fairhealthconsumer.org and fairhealthconsumidor.org. For more information on FAIR Health, visit fairhealth.org.

FAIR Health, Inc.
530 Fifth Avenue, 18th Floor
New York, NY 10036
212-370-0704
fairhealth.org
fairhealthconsumer.org
fairhealthconsumidor.org