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Lyme Disease Surveillance in New York State: an Assessment of Case Underreporting

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Summary

Despite the mandatory nature of Lyme disease (LD) reporting in New York State (NYS), it is believed that only a fraction of the LD cases diagnosed annually are reported to public health authorities. Lack of complete LD case reporting generally stems from (i) lack of report of provider-diagnosed cases where supportive laboratory testing is not ordered or results are negative (i.e. provider underreporting) and (ii) incomplete case information (clinical laboratory reporting only with no accompanying clinical information) such that cases are considered 'suspect' and not included in national and statewide case counts (i.e. case misclassification). In an attempt to better understand LD underreporting in NYS, a two-part study was conducted in 2011 using surveillance data from three counties. Case misclassification was assessed by obtaining medical records on suspect cases and reclassifying according to the surveillance case definition. To assess provider underreporting, lists of patients for whom ICD-9-CM code 088.81 (LD) had been used were reported to NYS Department of Health (NYSDOH). These lists were matched to the NYSDOH case reporting system, and medical records were requested on patients not previously reported; cases were then classified according to the case definition. When including both provider underreporting and case misclassification, approximately 20% (range 18.4–24.6%) more LD cases were identified in the three-county study area than were originally reported through standard surveillance. The additional cases represent a minimum percentage of unreported cases; the true percentage of unreported cases is likely higher. Unreported cases were more likely to have a history of erythema migrans (EM) rash and were more likely to be young paediatric cases. Results of the study support the assertion that LD cases are underreported in NYS. Initiatives to increase reporting should highlight the importance of reporting clinically diagnosed EM and be targeted to those providers most likely to diagnose LD, specifically providers treating paediatric patients.

Keywords

Lyme Disease; surveillance; underreporting

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Introduction

In New York State (NYS), over 120 000 cases of Lyme disease (LD) have been reported since LD became a notifiable condition in 1986. In the mid-1980s, the highest LD incidence in NYS was observed in the south-eastern part of the state on Long Island and in Westchester County (Hanrahan et al., 1984). Over time, the geographic range of LD spread north and west along the Hudson River (White et al., 1991); all 57 counties in upstate NY are now considered to be endemic for LD with areas of hyperendemicity in the Hudson Valley and areas of emergence in Central and Western NYS. Given the significant public health burden of LD, surveillance remains a priority.

Reporting of both provider-diagnosed LD cases and laboratory markers of LD are mandated under NYS law. The majority of LD cases in NYS are identified through public health investigation of positive LD laboratory reports, while provider reports are much less common. Although laboratory reporting in NYS is considered to be highly complete with 98% of laboratories reporting results electronically [D. DiCesare, NYS Department of Health (NYSDOH), personal communication], laboratory reports provide insufficient data to allow for case classification according to the national surveillance LD case definition [Council of State and Territorial Epidemiologists (CSTE), 2011]. Clinical information is critical for case classification, although this is often not provided by healthcare providers. Despite the mandatory nature of provider reporting in most states, it is believed that only a fraction of LD cases that are diagnosed annually are reported to public health authorities (Coyle et al., 1996; Meek et al., 1996; Orloski et al., 1998; CDC, 2013), although the degree of underreporting in NYS has not been previously quantified.

Under the NYS LD surveillance system, there are two potential avenues by which LD cases could be underreported: (i) lack of report of provider-diagnosed LD cases where supportive laboratory testing was not ordered or results were negative (i.e. provider underreporting) and (ii) incomplete case information (clinical laboratory reporting only with no accompanying clinical information) such that cases are considered ‘suspect’ and not included in national and statewide case counts (i.e. case misclassification). The goal of this study was to better understand the degree and nature of underreporting of LD in NYS (excluding New York City) using 2011 surveillance data from three upstate counties.

Methods

Three counties were selected for the study based on varying levels of LD endemicity and population: Albany (hyperendemicity/large population), Onondaga (emerging endemicity/large population) and Washington (emerging endemicity/small population) (Fig. 1). In 2011, NYSDOH staff conducted LD surveillance on behalf of local health departments (LHDs) in these counties. This involved investigating all positive LD laboratory reports reported to the NYSDOH Electronic Clinical Laboratory Reporting System or the LHDs directly by healthcare providers, following up with providers for clinical information via completion of a standardized case report form (CRF), classifying cases according to the 2011 LD national surveillance case definition (CSTE, 2011) and entering case reports into the NYSDOH Communicable Disease Electronic Surveillance System (CDESS). To inform the provider

underreporting portion of the study, existing LD CRFs were modified to include an area for providers to report the ICD-9-CM diagnosis codes associated with the patient's office visit or laboratory report. Reported ICD-9-CM diagnosis codes were analysed to determine the most frequently reported codes associated with LD case reports.

Case misclassification

For laboratory reports with no accompanying clinical information, associated providers were contacted a minimum of three times (telephone and mail) to request completion of CRFs. If after these attempts no CRF was received, NYSDOH staff requested each patient's medical record associated with the reported date of service or laboratory report. Information from medical records was then abstracted and entered onto the CRF. Cases were classified according to the 2011 LD national surveillance case definition and entered into CDESS. ICD-9-CM diagnosis code information reported on CRFs was analysed to determine the single most reported ICD-9-CM diagnosis code associated with LD cases in the three counties in 2011. Cases reported via standard surveillance were compared to cases identified through medical record review on such variables as sex, patient age and presenting symptoms. The additional percentage of cases identified via medical record review was also calculated.

Provider underreporting

A comprehensive list of healthcare providers/facilities in NYS was provided to NYSDOH study staff by the NYSDOH Office of Health Insurance Programs. This list was then reviewed by study staff to identify providers in areas/specialties most likely to diagnose LD. This subset included, but was not limited to, general practitioners, family practice providers, paediatricians, internists and dermatologists. Identified providers/facilities were contacted to determine the appropriate person to whom a survey about their coding and billing practices could be sent. The results of this survey are reported elsewhere in this issue (Thomas et al., this issue).

If a provider/facility reported the use of and ability to search for EMRs in the survey, NYSDOH study staff requested a list of all patients for whom a primary ICD-9-CM diagnosis code of 088.81 (LD) was used during 2011. This list was then matched with CDESS by name and date of birth to determine what, if any, cases had already been reported to NYSDOH. For patients who did not appear in the CDESS system, providers/facilities were asked to complete CRFs or, alternatively, to submit medical records on each patient. Cases were then classified by NYSDOH staff according to the 2011 LD national surveillance case definition and entered into CDESS. The additional percentage of cases identified via medical record review was calculated to determine the degree of provider underreporting in the three counties under study. Data were also analysed and compared by sex, patient age and presenting symptoms.

Results

In 2011, 2180 positive LD laboratory reports in Albany, Onondaga and Washington Counties were reported to NYSDOH for investigation (Table 1). Of these, 1452 (66.6%) did not

meet case definition (lack of a qualified laboratory assay, reports of asymptomatic patients, patients not diagnosed with LD per provider, etc.), 483 (22.2%) were initially classified as confirmed and probable cases, and 245 (11.2%) were determined to be suspect cases. One hundred and eighteen (48.2%) of these suspect cases resulted from a positive LD laboratory report without accompanying provider-reported clinical information. The remaining suspect cases were either due to lack of patient onset date associated with twotier, IgM-only, positive results or due to providers returning a CRF but reporting 'unknown' for all symptoms listed.

Case misclassification

Medical records were received for all suspect cases ($n = 118$) with no provider-reported clinical information on CRFs. Upon review of the medical records, 44 of the suspect cases (37.3%) did not meet case definition, 24 (20.3%) remained suspect, and 50 (42.4%) were found to be confirmed or probable cases. When including the 50 additional cases identified through medical record review as well as cases without accompanying laboratory results that were reported by healthcare providers [predominately erythema migrans (EM) rash cases], 722 LD confirmed and probable cases were identified in the counties under study. The confirmed and probable cases identified through medical record review represented a 7.4% overall increase in the number of confirmed and probable cases for 2011 (Table 1). In total, 875 confirmed, probable and suspect LD cases, including those reclassified in the misclassification portion of the study, were reported for Albany, Onondaga and Washington Counties in 2011.

The percentage of cases meeting the confirmed case definition was significantly different between cases identified through standard surveillance and those identified via misclassification study efforts. Forty per cent of cases identified through misclassification study efforts were confirmed compared to 79% of cases identified through standard surveillance (χ^2, $P < 0.0001$). In addition, cases identified through the misclassification study were less likely to have an EM rash (χ^2, $P < 0.0001$) or arthritis (χ^2, $P < 0.0001$) than cases identified through standard surveillance. There were no significant differences between the ages of cases identified through standard surveillance and those identified via misclassification study efforts.

Of the 875 confirmed, probable and suspect LD cases reported to NYSDOH by Albany, Onondaga and Washington counties in 2011[1], 273 (31.2%) were reported with associated ICD-9-CM codes. Of cases with reported codes, 114 (41.8%) had an associated code of 088.81 (LD). Other ICD-9-CM codes were also reported, although at much lower frequencies than 088.81; 'rash and other non-specific skin eruption' (782.1) and 'other malaise and fatigue' (780.79) were reported in 12.5% and 11.4% of cases with reported codes, respectively. Given that 088.81 was, by far, the most commonly reported ICD-9-CM code associated with reported LD cases, the decision was made to use 088.81 as the code most likely to identify LD cases during the provider underreporting portion of the study.

[1]Includes 672 confirmed/probable cases identified via standard surveillance, 127 cases that were originally identified as suspect but not reinvestigated due to the presence of clinical information, 74 cases that were upgraded to confirmed/probable following misclassification study efforts and two provider-reported suspect cases (Table 1).

Provider underreporting

Eighty-six healthcare providers/facilities were identified from the NYSDOH Office of Health Insurance Programs list and were contacted. A total of 49 (57.0%) healthcare providers/facilities participated in the underreporting portion of the study: Albany County ($n = 20$), Onondaga County ($n = 11$) and Washington County ($n = 18$). From the 49 providers/facilities, 2572 patients with ICD-9-CM diagnosis code 088.81 were reported (Fig. 2). As 1534 patients were excluded due to residence outside of the study counties (97.5%) or unknown county of residence (2.5%), a total of 1038 patients were matched with CDESS to determine whether they had previously been reported to NYSDOH. Of these, 539 (51.9%) had not previously been reported to NYSDOH, either in 2011 or a prior year. Medical records or completed CRFs were returned for 346 (64.2%) of these patients. Of the 346 medical records or completed CRFs reviewed, 248 (71.7%) did not meet the national surveillance case definition for LD, 92 (26.6%) were classified as confirmed, one (0.3%) was classified as probable, and one (0.3%) was classified as suspect; an additional four (1.2%) cases were reported in error. The additional confirmed and probable cases identified represented a 13.8% increase over standard surveillance (Albany: 8.7%, Onondaga: 15.0%, Washington: 20.0% increase) (Table 2).

Cases identified through the provider underreporting portion of the study more commonly had an EM rash than those identified through standard surveillance (Fisher's exact, $P < 0.0001$); however, they less commonly had arthritis compared to reported cases (Fisher's exact $P < 0.0001$). When comparing ages of cases reported to NYSDOH and those that were not reported, there were significantly more paediatric patients (age 0–10 years) in the unreported group (χ^2, $P < 0.05$).

Discussion

Although limited to only one ICD-9-CM code and three counties, the results of this study support the assertion that cases of LD are underreported in NYS. When including both LD case misclassification due to lack of clinical information and lack of healthcare provider reporting of diagnosed LD cases, just over 20% (range 18.4–24.6%) of LD cases in the three counties under study were not identified through standard surveillance (Table 3). While overall percentage increases in LD cases were fairly small in each of the three counties, it is important to note that overall, nearly 50% of cases that were originally classified as suspect were upgraded to either confirmed or probable cases following medical record review. Depending on the availability of resources, LD investigation and surveillance staff should consider requesting medical records on suspect cases in an attempt to minimize misclassification as was carried out in this study, especially in areas of NYS where LD is emerging.

Although percentage increases in LD cases varied somewhat by county, we believe these results to be generalizable across much of NYS in counties where LD is highly endemic or emerging, as the three counties chosen for study are representative of counties of varying population size and LD endemicity. Some of the variability in percentage increases may have been due to the number of healthcare providers/facilities participating in the underreporting portion of the study. As detailed in Thomas et al. in this issue, we believe that

Washington County had the highest percentage of providers participate in the underreporting portion of the study; this county also had the highest percentage increase in LD cases for the underreporting portion of the study.

Clinical differences were found between misclassified cases when compared to confirmed or probable cases originally identified via standard surveillance. Cases originally classified as suspect, but later upgraded in the misclassification study to confirmed/probable, were less likely to have the common symptoms of EM rash or arthritis. We speculate that the absence of typical LD clinical presentations may discourage healthcare providers from reporting cases to LHDs.

Differences were also found between unreported cases and cases that were reported to public health authorities. Unreported cases were much more likely to have an EM rash than reported cases, a finding similar to that described by Ertel et al. (2012) when comparing physician-based surveillance to laboratory-based surveillance. This is likely due to the fact that reported LD cases are most often identified through mandated reporting of positive laboratory results. Laboratory testing is not necessary for cases of physician-diagnosed EM rash with exposure in a LD endemic area, such as NYS. Unreported cases were less likely to have arthritis than reported cases. A similar finding was described by Ertel et al. (2012) when comparing case-patients reported through physician-based surveillance to those reported through laboratory-based surveillance. This, too, likely relates to laboratory reporting as arthritis can have many causes beyond LD with laboratory testing often being indicated to determine cause. In these cases, positive LD laboratory reports would have been reported to the LHD for investigation and case classification.

In addition, unreported cases were more likely to be paediatric (age ≤ 10 years) than reported cases. As virtually all unreported cases (both paediatric and adult) had had a history of EM rash, it is possible that healthcare providers seeing EM rash in paediatric patients are more likely to diagnose LD without ordering laboratory testing and without reporting the diagnosis to public health authorities than providers seeing rash in adult patients. The prevalence of underreporting among healthcare providers seeing paediatric patients and the presence of EM as diagnostic for LD could justify targeted provider education efforts to increase LD reporting among EM rash and paediatric cases.

There are several limitations to this study. Although we believe the results of this study to be generalizable across much of NYS in counties where LD is highly endemic or emerging (Fig. 1), we recognize that healthcare provider knowledge of LD and reporting requirements can vary and thus reasons for, and rates of, underreporting may vary. Providers in areas where LD has been endemic for over 30 years may experience ‘reporting fatigue’, while providers in emerging areas of the State with more limited experience in LD diagnosis may fail to report due to diagnostic uncertainty or lack of knowledge of reporting requirements. Further provider-based studies are needed to explore reasons for provider underreporting in both LD endemic and emerging areas.

The additional ~20% cases identified represents a minimum percentage of unreported cases; the true percentage of unreported cases is likely higher. In the misclassification phase of

the study, 1452 positive LD laboratory reports were found not to meet case definition. It is possible that some of these would have met case definition had the appropriate supportive information been provided or the appropriate laboratory testing ordered. In addition, medical records were requested only on suspect cases lacking provider responses; additional cases may have been identified if medical records had been requested on suspect cases with no reported onset date or all clinical information marked as 'unknown'.

In the underreporting phase of the study, use of a single ICD-9-CM code also likely led to an underestimate of the magnitude of underreporting as several ICD-9-CM codes can be used for patients with LD including rash, Bell's palsy, etc. In our analysis, only 41.8% of patients with LD were associated with ICD-9-CM code 088.81; incorporating other common ICD-CM codes associated with LD diagnoses would likely have led to the identification of additional unreported cases. It is also possible, however, that 088.81 was overreported among CRFs from providers reporting any codes.

Additional unreported cases would also have been identified if more providers had been willing to participate in the initial survey (Thomas et al.) and study. There were likely many more unreported cases from non-participating providers that this study cannot account for, including from providers who are unable to search for medical records electronically. Also, providers who participated in the study may be more likely to report LD cases to public health authorities than those who chose not to participate, potentially introducing selection bias. Although information was requested from participating providers on all patients not previously reported, information was not received on 35.8% of these patients (Fig. 2); many of these patients also likely met the case definition and would again have increased the magnitude of unreported cases.

Although only accounting for 2.5% of the cases that were excluded from analysis, cases from unknown counties may have been residents of the three counties under study and could also have added to the magnitude of underreporting. In addition, cases may have gone unreported if diagnosed outside of NYS; this potential underreporting factor was not assessed in this study but may be important, particularly in counties bordering neighbouring states.

Another limitation of the study involves case matching. Some patients that were reported by healthcare providers as having been diagnosed with LD (ICD-9-CM 088.81) may have been included in CDESS but not identified due to misspelling of names or incorrect dates of birth. Errors of this type may have led to a slight overestimate of unreported cases. Inconsistent reporting of diagnosis codes may also have served as a limitation to the study. Although we requested information only on patients for whom 088.81 was the primary diagnosis code, some providers were unable to separate primary and secondary diagnosis codes and sent us all patients who had been diagnosed with LD, whether LD was the primary diagnosis code or not. Other practices were able to distinguish between primary and secondary diagnosis codes, and only primary LD diagnoses were submitted to study staff for CDESS matching. Lastly, certain healthcare facilities (mainly hospitals) only had laboratory reports on file when medical records were requested in the underreporting portion of the study. These facilities provided lists of individuals with the 088.81 ICD-9-CM diagnosis code, but no

medical records beyond the laboratory results were available at the facilities. No confirmed or probable cases could be identified in these groups due to lack of clinical information, potentially leading to an underestimate of unreported cases.

Overall, while the magnitude may vary and the data presented represent a minimum percentage of unreported cases, this study supports the assertion that cases of LD are underreported in NYS. The NYSDOH and LHDs should continue to work to improve healthcare provider reporting of communicable diseases, including LD. Interventions aimed at increasing provider reporting should highlight the importance of reporting clinically diagnosed EM and be targeted to those providers most likely to diagnose LD, specifically providers treating paediatric patients. Future research on LD underreporting should include additional ICD-9-CM codes common to LD diagnosis and should attempt to elucidate the magnitude of unreported cases associated with each point of attrition noted in the limitations.

Researchers and healthcare decision-makers should be aware of the degree of LD underreporting when using published case counts as these counts tend to undervalue the public health significance of LD in NYS; LD consumes significantly more medical and public health resources than published case counts would suggest. Further evaluation will be needed to assess LD surveillance and reporting as these processes change with advancements in healthcare technology and service delivery.

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Impacts

- Cases of Lyme disease (LD) are thought to be underreported due, in part, to lack of provider reporting of diagnosed cases as well as lack of provision of clinical information leading to case misclassification.
- This study assessed both provider underreporting and case misclassification to better understand the degree and nature of LD underreporting in New York State (NYS).
- Results of the study support the assertion that LD cases are underreported in NYS. Initiatives to increase reporting should highlight the importance of reporting clinically diagnosed EM and be targeted to those providers most likely to diagnose LD, specifically providers treating paediatric patients.

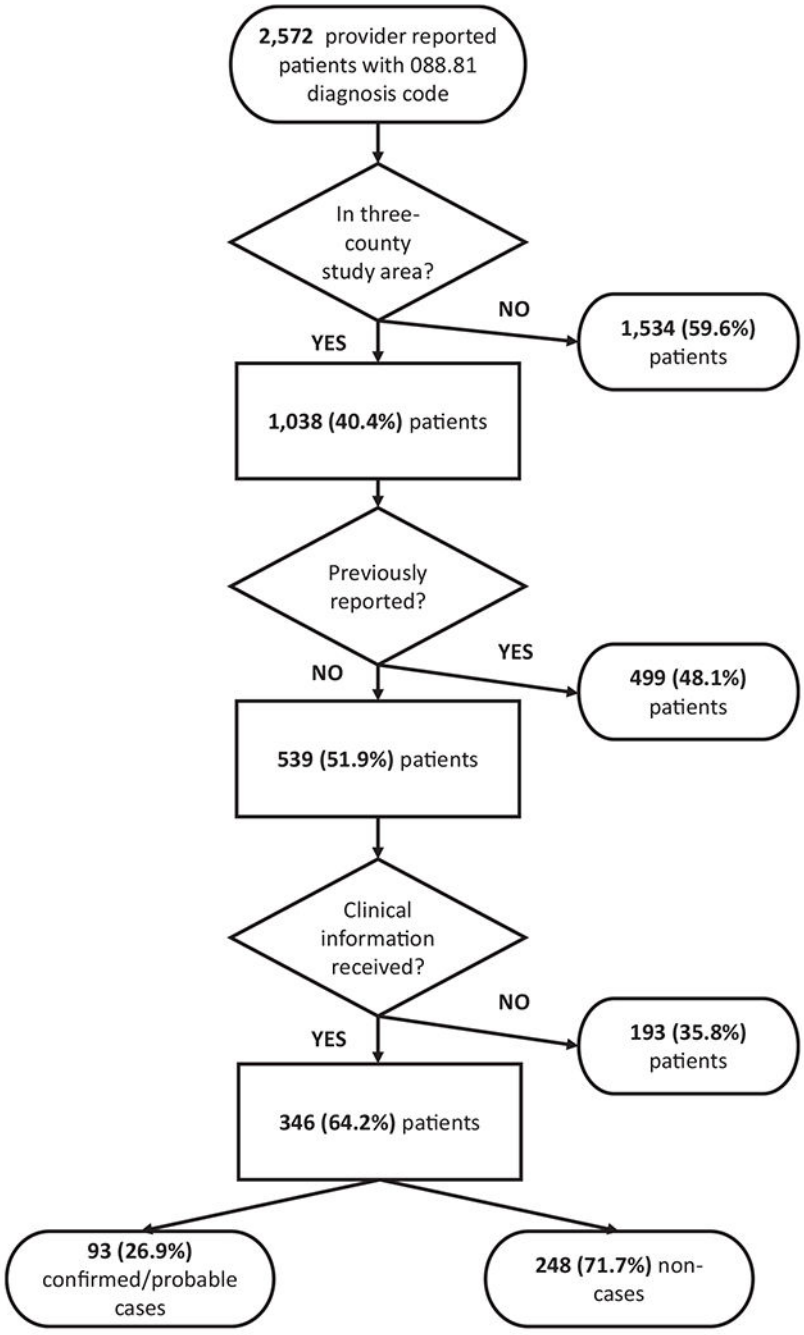

Fig. 1.

Dispensation of provider-reported patients diagnosed with Lyme disease (ICD-9-CM code 088.81): underreporting study, Albany, Onondaga and Washington Counties, New York State, 2011.

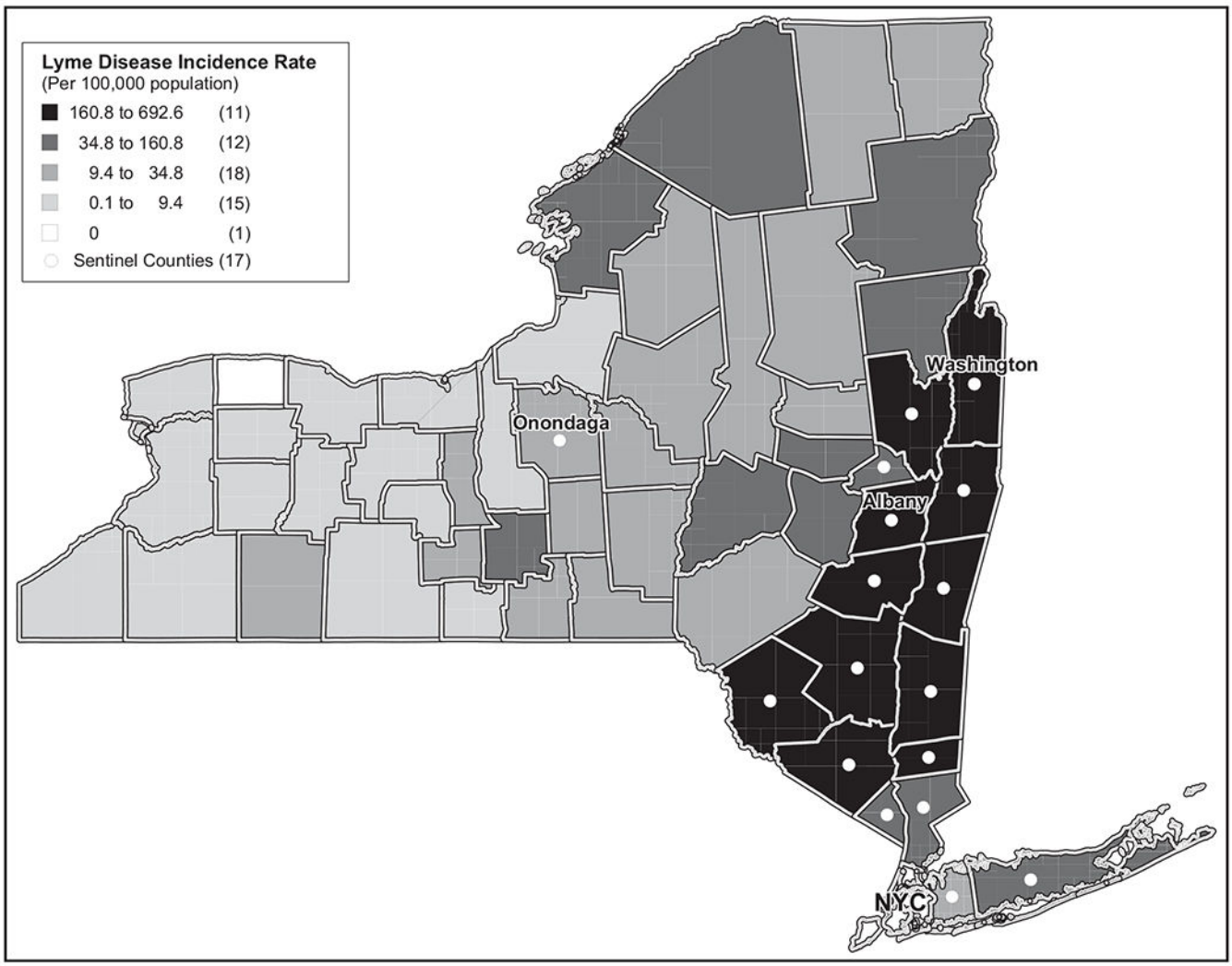

Fig. 2.

Three-year average LD annual incidence rates by county, New York State (excluding New York City), 2009–2011. Counties marked with a white circle participated in surveillance using sampling estimation in at least one of the 3 years. Range breaks were determined according to the natural break method such that the difference between the data values and the average of the data values is minimized on a per range basis.

Table 1.

Lyme disease cases identified through standard surveillance and misclassification study efforts and percent increase in case counts, Albany, Onondaga and Washington Counties, New York State, 2011

	Standard surveillance (laboratory report surveillance only)					Misclassification study efforts					
County	**Positive LD laboratory reports**	**No. (%) not meeting case definition**	**No. (%) initial confirmed/ probable cases**	**No. (%) initial suspect cases**	**No. (%) initial suspect cases with no clinical information**	**No. (%) cases upgraded to confirmed/ probable following MR review**	**No. (%) cases not meet case definition following MR review**	**No. (%) cases remaining suspect following MR review**	**Total no. confirmed/ probable cases – standard surveillance[b]**	**Total no. confirmed/ probable cases – standard surveillance[b] + misclassification study**	**Percent increase over standard surveillance (%)**
Albany	1386	939 (67.7)	302 (21.8)	145 (10.5)	69 (47.6)	32 (46.4)	23 (33.3)	14 (20.3)	332	364	9.6
Onondaga	383	261 (68.1)	71 (18.5)	51 (13.3)	25 (49.0)	6 (24.0)	15 (60.0)	4 (16.0)	80	86	7.5
Washington	411	252 (61.3)	110 (26.8)	49 (11.9)	24 (49.0)[a]	12 (50.0)	6 (25.0)	6 (25.0)	260	272	4.6
Total	2180	1452 (66.6)	483 (22.2)	245 (11.2)	118 (48.2)	50 (42.4)	44 (37.3)	24 (20.3)	672	722	7.4

[a] Does not Include two provider-reported suspect cases.

[b] Includes provider reported cases without accompanying laboratory testing.

Table 2.

Provider-reported Lyme disease cases through underreporting study efforts and percent increase in case counts, Albany, Onondaga and Washington Counties, New York State, 2011

County	No. of health care provider reported patients with 088.81 diagnosis code	No. (%) of atients in catchment area	No. (%) of patients not previously reported	Of patients not previously reported, no. (%) of patients for whom clinical information was received	Of patients for whom clinical information was received		Total no. confirmed/ probable cases – standard surveillance[b]	Total no. confirmed/ probable cases – standard surveillance[b] + underreporting study efforts	Per cent increase over standard surveillance (%)
					No. (%) of patients not classified as having LD[a]	No. (%) of patients meeting confirmed/ probable case definition[a]			
Albany	1319	388 (29.4)	213 (54.9)	165 (77.5)	132 (80.0)	29 (17.6)	332	361	8.7
Onondaga	87	63 (72.4)	31 (49.2)	27 (87.1)	14 (51.9)	12 (44.4)	80	92	15.0
Washington	1166	587 (50.3)	295 (50.3)	154 (52.2)	102 (66.2)	52 (33.8)	260	312	20.0
Total	2572	1038 (40.4)	539 (51.9)	346 (64.2)	248 (71.7)	93 (26.9)	672	765	13.8

[a]Based on the LD national surveillance case definition.

[b]Includes provider-reported cases without accompanying laboratory testing.

Table 3.

Per cent increase in Lyme disease case counts following misclassification efforts and underreporting study, Albany, Onondaga and Washington Counties, New York State, 2011

	Standard surveillance	Misclassification study efforts	Underreporting study efforts	Standard surveillance + misclassification study efforts + underreporting study efforts	
County	Total no. of confirmed/ probable LD cases identified[a]	No. of additional confirmed/ probable cases identified through misclassification efforts	No. of additional confirmed/ probable cases identified through underreporting study	Total no. of confirmed/probable LD cases identified[a]	Per cent increase over standard surveillance(%)
Albany	332	32	29	393	18.4
Onondaga	80	6	12	98	22.5
Washington	260	12	52	324	24.6
Total	672	50	93	815	21.3

[a]Includes provider-reported cases without accompanying laboratory testing.