ORIGINAL ARTICLE

Characterizing Lyme Disease Surveillance in an Endemic State

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Impacts

- Lyme disease (LD) surveillance practices vary across Maryland's 24 local health departments, which have suffered a reduction in personnel to conduct LD surveillance since 2011.
- Over time, local health departments have chosen to investigate only those reports that meet the criteria for laboratory evidence of infection, rather than investigating each and every LD report received.
- Despite there being several thousand Lyme disease reports investigated each year, several thousand more Lyme disease reports are not investigated and may not be entered into the state surveillance database each year, providing evidence that LD is underreported to public health agencies in Maryland.

Keywords:
Lyme disease; surveillance; public health

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Summary

Lyme disease (LD) is the most common vector-borne disease in Maryland and the United States. Surveillance for LD is valuable for understanding the burden of the disease, particularly to assess whether the disease is spreading and to appreciate who is affected. However, not all cases of LD in Maryland are reported, and surveillance practices vary across each of Maryland's 24 local health departments (LHDs). To better understand this variability and to systematically characterize the surveillance process, we surveyed Maryland's LHDs regarding LD surveillance. The Maryland Local Health Department Lyme Disease Surveillance Survey has been administered annually since 2011. Questions asked each year included whether all LD reports are investigated or only a subset, and how many reports are not entered into the surveillance database. Since 2011, Maryland has lost surveillance personnel for LD. Each year from 2009 to 2012, a median 3598 (range 2462 to 5722) reports were not entered into the surveillance database and hence not investigated. These reports represent 43–55% of all reports received for the year. Over time, more LHDs chose to streamline their LD investigation approach by investigating only those reports that met the criteria for laboratory evidence of infection: in 2008, 5 (21%) LHDs investigated only a subset of LD reports; by 2013, this increased to 15 (63%). There is wide variability across LHDs in how LD investigations are conducted. Maryland LHDs have experienced a loss of LD surveillance personnel with a concomitant increase in the number of LHDs adopting a streamlined approach to investigating cases. These findings underscore the tremendous burden of LD on the public health agencies and highlight the need for alternative approaches that can both reduce burden and preserve surveillance data quality.

Introduction

Lyme disease (LD) is the most common vector-borne disease in Maryland and the United States. In 2013, the Maryland Department of Health and Mental Hygiene (DHMH) reported that the statewide LD incidence rate was 20.2 confirmed and probable cases/100 000 persons (Maryland DHMH, 2013). Historically, Maryland has consistently been one of the 14 states contributing 95% of reported LD cases nationwide (CDC, 2014).

As with other reportable diseases, public health surveillance for LD is valuable to: i) understand the burden of the disease, ii) assess whether the disease is geographically spreading, and iii) determine who is affected. However, not all cases of LD in Maryland are reported to the local health departments (LHDs) and there is variability in surveillance practices at each of Maryland's 24 LHDs. To better understand the variability and to systematically characterize the surveillance process, we surveyed Maryland's LHDs regarding their individual LD surveillance processes and to explore reasons contributing to the variability.

Description of Programme

Maryland statutes and regulations require laboratories to report all positive LD test results and providers to report all LD cases to the LHD in the jurisdiction in which the patient resides (COMAR, 2015). The vast majority of reports come from laboratories; however, some providers report cases confirmed by clinical signs alone. When a laboratory submits a report, additional information from the provider or laboratory is requested by LHD staff to complete a surveillance case report form (CRF) and determine case classification. This information can include patient demographics, onset and diagnosis dates, signs and symptoms, and any additional test results. LHD staff use these data to classify the patient as confirmed, probable or suspected according to the national case definition for LD as determined by the Council of State and Territorial Epidemiologists (CDC, 2008). A report that does not meet these definitions, or if there is insufficient information to make a determination, is classified 'not a case'. Reports are entered into the Maryland National Electronic Disease Surveillance System (NEDSS) database which Maryland uses to electronically capture surveillance reports.

In 2008, responding to LHD surveillance staff requests to reduce the burden of LD surveillance, DHMH proposed a case investigation algorithm (Fig. 1), whereby LHDs could investigate only those laboratory reports that met the LD surveillance case definition criteria for 'laboratory evidence of infection', as opposed to investigating each and every laboratory report of LD. It was expected that staff time and resources would be conserved for those LHDs opting for this investigational approach, yet it was also recognized that some LD reports submitted by laboratories that could potentially be classified as confirmed or probable would not be investigated. As this approach was optional and LHDs were not required to convey their approach to DHMH, it was unknown how many LHDs adopted it. DHMH requested that all reports that were not investigated be filed by the LHDs with the understanding that DHMH could request information about those reports at a later date.

Methods

To better understand the complexities of LD surveillance in each of Maryland's 24 LHDs, the DHMH Emerging Infections Program first administered the Maryland Local Health Department Lyme Disease Surveillance Survey in 2011 and again in 2012 and 2013. The survey comprised multiple-choice, numeric and open-ended questions. Data captured included the number of LHD staff conducting LD surveillance, the investigation approach and the number of positive laboratory reports not entered into NEDSS; a final, open-ended question provided the opportunity for staff to describe other issues important to LD surveillance. Administering the survey annually allowed for additional questions to be tailored to issues occurring in a specific year, such as experiences with electronic laboratory reporting. The questionnaires were pretested by representatives of LHDs heavily engaged in LD surveillance and modified in response to their feedback. The initial survey, administered in 2011, requested information about reports not entered for each of the previous two years and practices for each year during the period 2009–2011. Subsequent surveys asked about current practices and the number of reports not entered into NEDSS for the previous year.

Department of Health and Mental Hygiene requested that the person most familiar with LD surveillance at each LHD complete the survey and suggested that, prior to completing the survey, respondents should determine the number of LD reports not entered into NEDSS during the previous year, the number of staff and estimated hours spent working on LD surveillance in the past year and the investigation approach the jurisdiction used for LD reports. The survey was intended to be completed in less than 20 min. Two to 3 weeks after the initial invitation, non-responding LHDs were sent reminder messages.

Results from the 2011, 2012 and 2013 surveys were combined for questions asked in all years. In 2013, the question regarding the number of staff involved in LD surveillance was asked differently than in prior years with the intention of making it easier to respond accurately. Data were summarized using Microsoft Excel (2007). Analysis was primarily descriptive. Chi-square tests were conducted in OpenEpi to assess the effect of investigation approach on case classification, and Wilcoxon rank-sum tests were conducted using Stata12 to compare attempts to contact providers by investigation approach.

Results

In each year, all 24 LHDs completed the surveys within 6 weeks of being invited, for a 100% survey response rate.

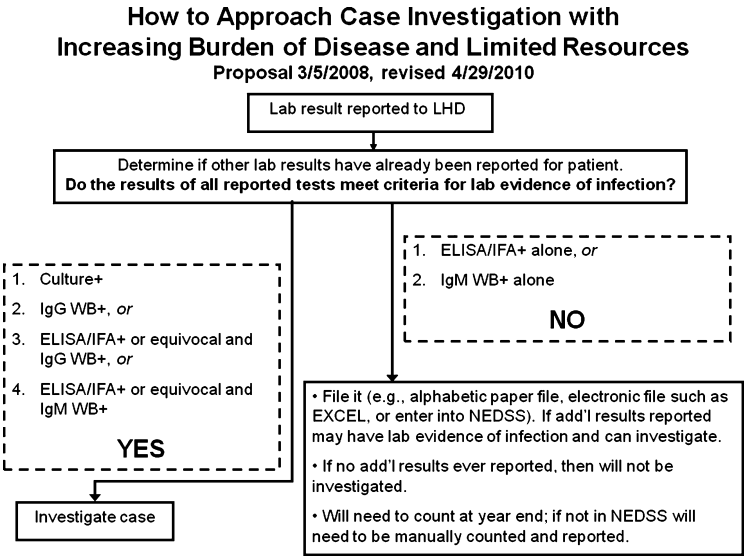

Fig. 1. DHMH Proposed LD Investigation Algorithm for Laboratory Reports.

Lyme disease reports not in NEDSS

For jurisdictions using the DHMH investigation algorithm, laboratory reports not meeting the investigation criteria are not investigated and, although retained for record keeping, may not be entered into NEDSS. The number of reports not entered into NEDSS each year ranged from 2462 (in 2011) to 5722 (in 2009) (Table 1). When combined with the number of reports in NEDSS, the total number of LD reports submitted annually to LHDs ranged from 5764 (in 2011) to 10 490 (in 2009).

Investigation approach and surveillance

Local health departments were asked which investigative approach they used for each year since the algorithm was introduced in 2008 (Fig. 2). In 2008, only 5 (21%) LHDs used the DHMH investigation algorithm for investigations, but by 2013 this number increased to 15 (63%). LHDs selected 'Other/Don't Know' when they changed their investigative approach during the year (e.g. one LHD reported that in 2009, staff could not keep up with LD surveillance due to the need to respond to the influenza A H1N1 pandemic), the person completing the survey did not know what was done in prior years, or when another investigation approach was used.

We examined how the different investigation approaches (use of the algorithm versus investigating all reports) used by LHDs for the years 2010–2012 affected case classifications of reports entered into NEDSS (Table 2). This analysis excluded reports from LHDs that selected Other/Don't Know for their investigative approach. Of the total reports (2649) entered into NEDSS for 2010 by LHDs that selected either 'investigate all' or were 'algorithm users', 1503 (57%) were entered by the 10 LHDs that followed the DHMH investigation algorithm and 1146 (43%) were entered by the 11 LHDs that investigated all reports (484 reports were entered into NEDSS by LHDs that selected Other/Don't Know and were therefore excluded from this analysis). The LHDs using the DHMH investigation algorithm classified a significantly greater proportion (64%) of their LD cases in NEDSS as confirmed or probable as compared to the LHDs investigating all reports (46%) ($\chi^2 = 87.9$, $P < 0.001$). In 2011, of the total reports (3223) entered into NEDSS by LHDs that selected either 'investigate all' or the 'algorithm users', the 10 LHDs using the DHMH investigation algorithm entered 2071 (64%) of all reports. These 10 LHDs classified a slightly higher proportion (42%) of their cases as confirmed or probable when compared to the 12 LHDs investigating all reports (40%), but these proportions were not significantly different ($\chi^2 = 1.6$, $P = 0.2$). By 2012, of all reports (4907) entered into NEDSS by LHDs that selected either 'investigate all' or were 'algorithm users', 13 LHDs following the DHMH investigation algorithm entered 3822 (78%) of all reports in NEDSS. These LHDs classified 32% of cases as confirmed or probable while the 9

Table 1. Total LD Reports Submitted to LHDs, 2009–2012[a]

	2009	2010	2011	2012
No. of Reports in NEDSS	4768	3133	3302	5227
No. of LD Reports Not Entered into NEDSS	5722	2951	2462	4244
Total No. of LD Reports for Year	10 490	6084	5764	9471

[a]The 2011 survey captured the number of reports not entered into NEDSS for 2009 and 2010. Subsequent surveys asked about the number of reports not entered into NEDSS for the previous year.

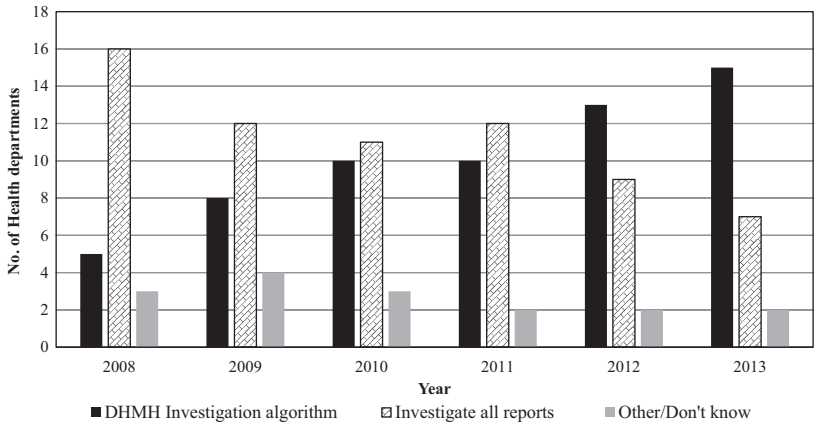

Fig. 2. Health Department LD Investigation Approaches, 2008–2013[A]. [A]The 2011 survey captured the investigation approach for 2008–2011. Subsequent surveys asked about the current investigation approach for the year the survey was administered.

LHDs investigating all reports classified 29% as such; again, these proportions were not significantly different ($\chi^2 = 3.3$, $P = 0.07$).

However, when considering all LD reports received at the LHDs (including those not entered into NEDSS), those LHDs investigating all LD reports classified a greater proportion as confirmed and probable cases than the LHDs that used the algorithm, and this was significant for all three years. The proportion of confirmed and probable cases classified by the LHDs investigating all reports was significantly higher, ranging from 28% to 45% of all reports received. The LHDs that used the investigation algorithm classified 15% to 23% of all reports received each year as confirmed or probable.

Case classification process

To better characterize the investigation process, the 2011 survey asked for the frequency of attempts made by LHD staff to contact providers for additional patient information, whether by letter, fax or telephone call. For all LHDs, the median number of attempts to contact a provider for more information was two (range 1–4) attempts. Four (17%) LHDs made only one attempt to contact providers. The median number of attempts to contact providers for additional patient information for DHMH investigation algorithm users was two (range 1–4) when compared to three (range 1–4) for LHDs investigating all reports ($P = 0.02$).

Electronic laboratory reports

In late 2011, electronic laboratory reporting of reportable conditions to public health agencies expanded from one low-volume commercial laboratory to also include one high-volume commercial laboratory. With the expansion of electronic reporting, the 2012 survey included a series of questions about interpreting test results reported electronically, the ease of processing electronic laboratory reports, whether electronic reporting saved time for LHD staff, and overall satisfaction with electronic versus paper reporting.

We found that electronic reporting is viewed favourably by respondents in general, but with caveats. Electronic reporting has helped with populating patient demographic information into NEDSS, thus reducing data entry and expediting internal report processing. However, there was no difference in ease of interpreting test results with electronic versus paper reports. In addition, some LHDs print and file electronic reports, so electronic reporting has not decreased the workload, or processing of paper. Also, in some cases and as with paper reports, staff must call laboratories to request additional testing information in order to classify cases.

Surveillance resources

From 2011–2013, the number of personnel conducting LD surveillance dropped from 56 to 43 persons (Table 3). None of the LHDs had a staff member solely dedicated to LD surveillance, and in 2011, one LHD did not have any staff members working on LD surveillance. As the number of total employees engaged in LD surveillance across all LHDs decreased from 2011, the median number and range of hours worked each week on LD surveillance increased in 2012.

In 2011, 14 (58%) LHDs responded that nurses solely entered data for LD surveillance, and in 2012, 13 (54%) LHDs responded that nurses solely conducted data entry. In 2011, 2 (8%) LHDs relied on clerical staff for NEDSS data entry and that increased to 4 (17%) in 2012. Nurses and clerical staff shared data entry responsibilities for six (25%) LHDs in 2011 and for seven (29%) LHDs in 2012. Epidemiologists entered data for two (8%) LHDs in 2011.

Table 2. Proportion Confirmed and Probable LD Reports by Investigation Approach (Excluding Reports from LHDs that Selected "Other/Don't Know" as the Investigation Approach) and Year of Report, 2010–2012 (n = number LHDs)[a]

	LD Reports Entered into NEDSS					All LD Reports Received			
	Confirmed and Probable	Suspected and Not a case	Total in NEDSS	Proportion Confirmed and Probable	χ^2, P-Value	Reports Not in NEDSS	Total LD Reports	Proportion Confirmed and Probable	χ^2, P-Value
2010									
Investigate All Reports (n = 11)	526	620	1146	46%	87.9, ≤0.001*	34	1180	45%	243.5, ≤0.001*
Algorithm Users (n = 10)	964	539	1503	64%		2892	4395	22%	
2011									
Investigate All Reports (n = 12)	463	689	1152	40%	1.6, 0.20	14	1166	40%	123.3, ≤0.001*
Algorithm Users (n = 10)	880	1191	2071	42%		1724	3795	23%	
2012									
Investigate All Reports (n = 9)	318	767	1085	29%	3.3, 0.07	40	1125	28%	117, ≤0.001*
Algorithm Users (n = 13)	1232	2590	3822	32%		4204	8026	15%	

*Significant.

[a]Data are presented by year of report in NEDSS. Data for 2010 were captured in the survey administered in 2011; data for 2011 were captured in the 2012 survey; and 2012 data were captured in the 2013 survey.

Table 3. LHD Staff Resources for LD Surveillance, 2011–2013[a]

	2011	2012	2013[b]
Number of Employees Conducting LD Surveillance	56	53	43
Median Number Employees conducting LD Surveillance per LHD (range)	2 (0–5)	2 (1–4)	1 (1–4)
Median Hours per Week per Employee (range)	2.42 (0–22)	3 (0.5–30)	N/A
Median Years of Experience (range)	4 (0–33)	5 (0.5–34)	N/A

[a]Surveys asked about current staffing levels for the year the survey was administered.

[b]In 2013, the survey collected data about FTEs only, whereas in 2011 and 2012, surveys collected the hours worked per week and years of experience.

Staff thoughts regarding Lyme disease surveillance

For each year, the final open-ended question on the survey allowed staff to discuss any issues regarding LD surveillance. Responses collected from all three years were characterized by one of five common themes. These included: frustration with the lack of clinical information given by providers; need for more provider training regarding LD; resource-intensive nature of LD surveillance; declining resources available for LD surveillance; and questions about whether LD surveillance is necessary given that LD is not transmissible from person-to-person nor requires an immediate intervention to prevent additional transmission.

Discussion

Overall, there is wide variability across Maryland's 24 LHDs in how LD surveillance is conducted, which increases the complexity of interpreting LD surveillance data, both within Maryland and in comparison to other states. The results of these surveys help characterize that variability and allow for a greater appreciation of the true burden of LD surveillance for Maryland's LHDs.

At the time of our first survey, 10 LHDs were streamlining their surveillance approach using the DHMH investigation algorithm. By 2013, an additional five LHDs adopted the DHMH investigation algorithm and those LHDs who used the algorithm also reported making fewer attempts to

reach providers for data. During this same time period, LHDs indicated a net loss of personnel engaged in LD surveillance, which was echoed in the qualitative comments regarding the reduced staff available to conduct LD investigations. With ongoing concerns about staff resources and the multiple responsibilities for staff, more LHDs may opt to streamline their investigation approach in the future.

The large number of reports that were not entered into NEDSS suggests that a much larger pool of Maryland residents may have been infected with LD than is indicated by surveillance statistics reported by public health agencies. This underscores the likelihood that the number of LD cases captured by public health agencies is less than what actually occurs in Maryland. Notably, there were twice as many LD reports not entered into NEDSS in 2009 and 2012, as compared to reports not entered into 2010 and 2011. While these numbers may reflect a true increase of disease in those years, in 2009, we know that one LHD sent letters to local providers reminding them to report LD. However, that same year the LHD also reported being unable to keep up with LD investigations because of the influenza A H1N1 pandemic and other local infectious disease issues. In late 2011, a large commercial laboratory began sending LD test results to LHDs electronically, which may explain the increase in LD reports in 2012.

If we consider that the findings for the LHDs that investigated all reports represent the true proportion that would be confirmed or probable, we would expect 28–45% of all reports received to be classified as such. If we conservatively apply the lower value of this range (28%) to all reports received by LHDs that used the algorithm during 2010–2012 (4395, 3795 and 8026 for those years respectively), we would expect a total of 4540 confirmed and probable cases in those jurisdictions over those three years. There are 3076 confirmed and probable cases captured in NEDSS for those jurisdictions, and therefore, the projected 4540 confirmed and probable cases represent an increase of 1464 confirmed or probable cases, or a 48% increase. Thus, opting to streamline the surveillance approach may ease the burden on staff, but at a cost to the reported number of LD cases. However, LHDs may consider this cost worthwhile, given that reporting the reduced number still reflects important epidemiologic trends. Our findings provide evidence for the underreporting of LD cases to public health agencies and also document the tremendous burden of LD surveillance on the public health system, regardless of whether all reports are investigated.

Electronic reporting of laboratory results was introduced over the time period we evaluated, and we assessed its acceptance by the LHDs. While we found that electronic reporting did not accelerate LD investigations, it did facilitate clerical work and eliminate certain administrative tasks such as data entry. As the number of laboratories that report electronically continues to rise, there will likely be a concomitant increase in the number of LD reports in our database. If some of the administrative tasks, such as data entry, are lessened, perhaps more time can be dedicated to investigating the reports.

Surveillance staff frequently mentioned that more LD training is needed for providers in order to increase provider reporting to LHDs. The reasons that providers do not report clinically diagnosed cases of LD were not explored in this survey; however, if providers do not report LD to LHDs because it is too burdensome, then additional training for providers may not resolve the issue of underreporting to public health agencies. Training could perhaps increase providers' knowledge of appropriate tests and treatment for LD, but may be better provided by clinical entities rather than public health agencies.

Survey respondents questioned the overall utility of conducting LD surveillance. Investigating reports of LD involves compiling information (patient demographics, disease onset, signs and symptoms, multiple laboratory results, and physician diagnosis) from numerous data sources. Classifying LD cases requires interpreting and synthesizing clinical and diagnostic data. While LD surveillance data allow public health authorities to identify modifiable risk factors and target interventions demographically, geographically, and seasonally, there is no immediate intervention implemented when a LD case is identified. As a result, LD surveillance activities may be given a lower priority than surveillance for other acute communicable diseases that warrant immediate intervention when a case is identified.

Lyme disease surveillance is a complex activity in Maryland, and this statement is underscored by our finding that nurses conduct much of the LD surveillance, rather than clerical staff or other personnel who do not have clinical training. The challenge in balancing the resource intensiveness of LD surveillance with the valuable knowledge gained from surveillance data further underscores the need to identify alternative approaches to conducting LD surveillance, instead of investigating each and every report. Potential approaches, such as investigating only a systematic sample of reports (Bjork and Brown, 2016; this issue; Lukacik and White, 2016; this issue) or querying billing databases for LD diagnoses (Rutz et al., 2016, this issue), are being explored as options to alleviate the burden of LD surveillance on the public health system while retaining the insights gained from this essential public health function.

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Conflict of Interest

The authors have no conflict of interests to declare.

References

Bjork, J., and K. Brown, 2016: A retrospective analysis of an estimating procedures for Lyme disease surveillance in Massachusetts and Minnesota. *Zoonoses Public Health*.

CDC, 2008: Lyme disease 2008 Case Definition. Available at: http://wwwn.cdc.gov/NNDSS/script/casedef.aspx?CondYrID=751&DatePub=2008-01-01 (accessed on 24 February 2015).

CDC, 2014: Lyme Disease Cases by State. Available at: http://www.cdc.gov/lyme/stats/chartstables/reportedcases_statelocality.html (accessed on 24 February 2015).

COMAR, 2015: Reportable Diseases, Conditions, Outbreaks, and Unusual Manifestations; Submitting Clinical Materials. Available at: http://www.dsd.state.md.us/comar/getfile.aspx?file=10.06.01.03.htm (accessed on 24 February 2015).

Lukacik, G., and J. White, 2016: Evaluation of an estimating procedure for Lyme disease surveillance in New York state. *Zoonoses Public Health*.

Maryland DHMH, 2013. Lyme Disease in Maryland by Jurisdiction: 2000-2013. Available at: http://phpa.dhmh.maryland.gov/IDEHASharedDocuments/2013Rates.pdf (accessed on 24 February 2015).

Rutz, H., B. Hogan, A. Hinckley, and K. Feldman, 2016: Exploring an alternative approach to Lyme disease surveillance in Maryland. *Zoonoses Public Health*.

