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OPINION

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Lyme disease surveillance in the United States: Looking for ways to cut the Gordian knot

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Summary

Current surveillance methods have been useful to document geographic expansion of Lyme disease in the United States and to monitor the increasing incidence of this major public health problem. Nevertheless, these approaches are resource-intensive, generate results that are difficult to compare across jurisdictions, and measure less than the total burden of disease. By adopting more efficient methods, resources could be diverted instead to education of at-risk populations and new approaches to prevention. In this special issue of Zoonoses and Public Health, seven articles are presented that either evaluate traditional Lyme disease surveillance methods or explore alternatives that have the potential to be less costly, more reliable, and sustainable. Twenty-five years have passed since Lyme disease became a notifiable condition – it is time to reevaluate the purpose and goals of national surveillance.

KEYWORDS

alternative, *Borrelia burgdorferi*, human, Lyme disease, surveillance, underreporting

Public health surveillance is the ongoing collection, analysis and dissemination of data, with a primary goal of providing data for action that can be used to guide public health policies and programs (Hoinville et al., 2013; Smith, Hadler, Stanbury, Rolfs, & Hopkins, 2013). In 1991, Lyme disease became a nationally notifiable disease in the United States. Collection and analysis of surveillance data have enabled public health authorities to define the demographics and distribution of Lyme disease and to understand trends (Bacon, Kugeler, & Mead, 2008). Data have been used to inform prevention campaigns, programs and research.

Approximately 30,000 confirmed and probable cases of Lyme disease are reported annually to the Centers for Disease Control and Prevention (CDC) by state health departments, the District of Columbia and US territories. Lyme disease occurs in geographic areas in which the infected vectors, *Ixodes scapularis* and *Ixodes pacificus*, reside. Fourteen eastern and mid-western states (Connecticut, Delaware, Maine, Massachusetts, Maryland, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virginia and Wisconsin) report more than 96% of cases (Mead, 2015). It is well recognized, however, that the number of reported cases do not reflect every case of Lyme disease that occurs (Hinckley et al., 2014; Nelson et al., 2015). The system for reportable diseases works best for diseases that are either rare in occurrence, involve hospitalized patients, or for which there are definitive diagnostic laboratory tests. The system works less well for diseases that are common, diagnosed in outpatient settings, and for which there are no definitive diagnostic laboratory tests. Underreporting of the latter group, including Lyme disease, is common (Coyle et al., 1996; Matteson, Beckett, O'Fallon, Melton, & Duffy, 1992; Meek, Roberts, Smith, & Cartter, 1996; Naleway, Belongia, Kazmierczak, Greenlee, & Davis, 2002; Orloski et al., 1998). Unlike many of the diseases that are nationally notifiable, surveillance for Lyme disease in the United States is generally not conducted to elicit a public health action after identification of cases, but rather to systematically monitor the occurrence and trends of the disease, such as geographic expansion (Kugeler, Farley, Forrester, & Mead, 2015), and to assess the effectiveness of potential control measures on a population. Ultimately, however, significant underreporting can obscure trends and may inhibit the ability to evaluate the effectiveness of an intervention.

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This special issue of *Zoonoses and Public Health* presents several evaluations of traditional Lyme disease surveillance and several alternative methods, exploring their potential to meet surveillance objectives. To assess the issue of underreporting, Schiffman et al. describe a study conducted in a single, highly endemic county in Minnesota in 2009. The authors used diagnostic and procedure billing codes suggestive of tick-borne disease to identify medical records for review in an attempt to quantify the level of underreporting. They found a large number of unreported cases that comprised physician-diagnosed erythema migrans (EM) without laboratory testing. Including those cases increased the number of confirmed Lyme disease in that county by 180%. White et al. evaluated several sources of misclassification and underreporting in New York State in three counties with varying degrees of endemicity in 2011. The authors reviewed medical records from all laboratory-reported cases (potential misclassification) and patients of selected providers who had a diagnostic code for Lyme disease (underreporting). They identified at least 20% more Lyme disease cases than what had been reported, including many with physician-diagnosed EM and no serology, especially among paediatric patients. One suspected reason for underreporting was reporting fatigue because the disease is so common in these areas. Rutz and Feldman evaluated reporting in Maryland and found that partly because of diminishing personnel resources, local public health staff only investigated about half of the reports, generally those that met laboratory criteria for evidence of infection.

To address the current resource burden in conducting surveillance and to create more sustainable Lyme disease surveillance systems, some states have modified their approach. These changes have brought significant differences in effort being put forth across jurisdictions, generating results that are difficult to compare across jurisdictions and potentially impacting the validity of the surveillance information. To better understand the impacts, Lukacik et al. evaluated the New York State system in which case investigation is done on a random sample of 20% of positive laboratory reports in the counties that account for 90% of cases. Estimated case counts were compared with observed case counts from traditional surveillance for select counties over a 4-year period. The system was found to be accurate and efficient in estimating the number of cases at the county level. Bjork and Brown et al. retrospectively evaluated the reliability and validity of using a sampling approach of laboratory reports (similar to the procedure done in New York State), compared with traditional Lyme disease surveillance methods, in Massachusetts and Minnesota from 2005 to 2012. These investigators found that estimated case counts were similar to observed counts and conveyed temporal trends. Most demographic and clinical characteristics were not significantly different (although a 20% random sampling approach had more deviation than a 50% random sampling approach). These studies demonstrate that sampling and the resulting estimates can provide a useful approach for surveillance in areas that have a high burden of disease.

The traditional passive surveillance system for Lyme disease remains useful for monitoring trends and geographic spread, but it does not measure the total burden of disease. The advent of electronic health information systems has the potential to radically alter how surveillance for Lyme disease is done (Birkhead, Klompas, & Shah, 2015). These electronic systems make it possible for public health practitioners to track the number of persons who are diagnosed and treated for Lyme disease, obviating the need for clinicians to complete written reports and send to local and state health departments. This can alleviate issues of reporting fatigue and resources, but is this currently practical and does it increase the accuracy of the surveillance system for Lyme disease?

Impacts

- Current surveillance methods for Lyme disease are useful, but require significant resources to generate results that can be difficult to compare across jurisdictions.
- In this special issue of *Zoonoses and Public Health*, the authors of seven articles evaluate traditional Lyme disease surveillance and explore alternatives that have the potential to be less costly, more reliable, and sustainable.
- It is time to reevaluate the purpose and goals of national surveillance for Lyme disease.

To address this question, Thomas et al. surveyed selected healthcare facilities in Maryland and New York to assess the feasibility of using diagnostic codes to report Lyme disease. Most facilities were able to search for patient visits using specific diagnostic and billing codes; however, there was variation in the practice of code assignment and validation. Another report by Rutz et al. in Maryland evaluated the accuracy of using the Lyme disease diagnostic code to identify Lyme disease cases from administrative data sets and found a sensitivity of 37% and a specificity of 73%. Adding additional codes increased the sensitivity to 74%, but decreased the specificity to 37%. These studies suggest that diagnostic codes alone are not an expedient surveillance tool for Lyme disease. It is possible, however, that other forms of electronic health information (e.g. prescription drug data) could be used alone or in combination with administrative data sets to provide a more accurate and efficient alternative to traditional Lyme disease surveillance.

One of the guiding principles of public health surveillance is that surveillance systems should be periodically evaluated so that they remain useful. Important considerations are resource availability and sustainability, and surveillance efforts should address high-priority problems and those most amenable to intervention (Smith et al., 2013). Similarly, surveillance needs may be different in high- versus low-incidence states. For example, does a state have so few cases that investigating every case is feasible and important to ensure that changes in local epidemiology are captured? Or is a state's burden of disease high and has incidence remained stable for many years? Would an evaluation of prevention and control measures warrant a surveillance system with investigation of every reported case? In 2016, following an evaluation by a vector-borne disease subcommittee, the Council of State and Territorial Epidemiologists (CSTE) voted to modify the Lyme disease surveillance case definition so that "high-"

and "low"-incidence states are defined and, for low-incidence states, all confirmed cases be supported by laboratory evidence. For high-incidence states, the same committee is currently considering the use of a sampling strategy as a reasonable alternative to more traditional and labour-intensive surveillance methods. However, additional validation studies (similar to Lukacik, et al.) to assess the limitations of this approach may be necessary.

In theory, counting incident cases of an emerging infectious disease should be straightforward, but this has not been the case for Lyme disease surveillance, which continues to be a Gordian knot in the practice of public health. This seemingly intractable problem stems from the inability of traditional surveillance to sustainably and accurately measure the burden of disease. A unified approach to surveillance that meets the needs and surveillance objectives of both high- and low-incidence states has been elusive. If states use different surveillance methods, and accuracy is impacted by underreporting, how does this impact a condition that is nationally notifiable? It is essential to understand the systems being used to conduct Lyme disease surveillance and their precision from a national perspective. Twenty-five years have passed since Lyme disease became a notifiable condition—it is time to consider and reassess the objectives and outcomes of national surveillance for Lyme disease to ensure they are fit for purpose now and for the foreseeable future (Groseclose & Buckeridge, 2017).

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