Scrutinising Lyme disease in the UK

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Concerns over Lyme disease in the UK have been gaining attention. Most recently a study in *BMJ Open* by Victoria Cairns and colleagues received broad coverage in the press. This study reported that the incidence of the disease was three times higher than that of previous estimates and that people throughout the UK are at risk. This is clearly an attention grabbing finding. However, this conclusion might not be as clear-cut as it seems and, given the passionate advocacy associated with this disease, it is essential that care is taken over findings that could influence perceptions of its scale.

Cairns and colleagues set the scene by highlighting the importance of Lyme disease as "the most common tickborne infection in many parts of Europe and the USA", the effect of which is potentially underappreciated. A WHO report noted that many infections go unrecognised because of inconsistent and incomplete diagnostic methods. This information set the backdrop for the study, which used general practitioner records to explore whether official figures are a genuine underestimate. Cairns and colleagues concluded that the true number of cases was much higher than the official figure of 2000–3000 new cases per year, and that cases are widely distributed nationally.

However, in a critique of the study, Eugene Shapiro offered a different perspective. He explained that the UK relies on laboratory-based surveillance, which does not lend itself to accurate incidence estimation because it can miss many patients. Most patients who present with erythema migrans, the feature most commonly used to diagnose Lyme disease, will have negative antibody results. Compounding the potential confusion is that antibody assays for Lyme disease are highly likely to yield false-positive results in patients with no clinical evidence of the disease who have a low probability of infection.

Shapiro's specific criticism of the study by Cairns and colleagues related to the inclusion in their case definition of patients who were tested and treated irrespective of their test results. The problem here is that the number treated far exceeds the number of those with the infection. So, although official estimates are accepted to be too low, the methods used in this study probably led to overestimation. This overestimation might drive unnecessary testing and hence find more false positives, which could in turn lead to further overestimation of the incidence of the disease. There is potentially a need for diagnostic and treatment criteria that go further than the existing, already robust, NICE guidelines. The lack of clarity over the scale of Lyme disease has meant that the true effect has long been a topic of some controversy. In 2011, in *The Lancet Infectious Diseases*, Paul Auwaerter and colleagues outlined what they described as the anti-scientific concepts surrounding this disease that have been able to flourish given the perceived scarcity of definitive data.

Published at the same time as Cairns and colleagues' study, also in *BMJ Open*, was an assessment of the underlying demographics and geographical distribution of laboratory-confirmed Lyme disease in the UK by John Tulloch and colleagues. Shown more clearly than in the incidence study, because of their use of confirmed infection data, the findings show that people in rural areas of southern England are at the greatest risk, with cases being more likely in relatively affluent areas. These findings match earlier assessments of regional distribution and allow authorities to more accurately target resources. Despite the broad national distribution of the vector, the risk of infection in other areas was found to be low.

An important feature of the study by Tulloch and colleagues is that they discuss effects on distribution that go beyond climate extrapolations by factoring in changes such as in land management and human activity. In this issue of *The Lancet Infectious Diseases*, a Review by Lydia Franklinos and colleagues sets out the broader characteristics of global change that must be factored into analyses of disease vectors. Although they focus on mosquitoes, these considerations have relevance for other vector organisms.

As Shapiro concluded, if it is accepted that establishing the true incidence of Lyme disease in the UK and elsewhere is desirable, then better surveillance methods are needed. Improvements are being explored in an ongoing international consultation of infectious disease societies. Revised guidelines might bring the clarity needed to pin down the scale of the disease; however, stricter criteria for diagnosis and treatment will inevitably leave some advocates unsatisfied.

■ *The Lancet Infectious Diseases*

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For more on **Cairn's incidence study** see *BMJ Open* 2019; **9:** e025916. DOI:10.1136/bmjopen-2018-025916

For the **WHO report on Lyme disease in Europe** see http://www.euro.who.int/en/publications/abstracts/lyme-borreliosis-in-europe.-influences-of-climate-and-climate-change,-epidemiology,-ecology-and-adaptation-measures

For **Shapiro's critique** see https://www.healio.com/infectious-disease/emerging-diseases/news/online/%7B18f59b0c-3d16-4e7b-b68e-7a37653bf855%7D/lyme-disease-incidence-three-times-higher-in-uk-than-previously-thought-study-suggests

For the **NICE guidance** see https://www.nice.org.uk/guidance/ng95

For more on **Auwaerter on Lyme disease** see **Personal View** *Lancet Infect Dis* 2011; **11:** 713–19

For more on **Tulloch's ecological study** see *BMJ Open* 2019; **9:** e028064. DOI:10.1136/bmjopen-2018-028064