

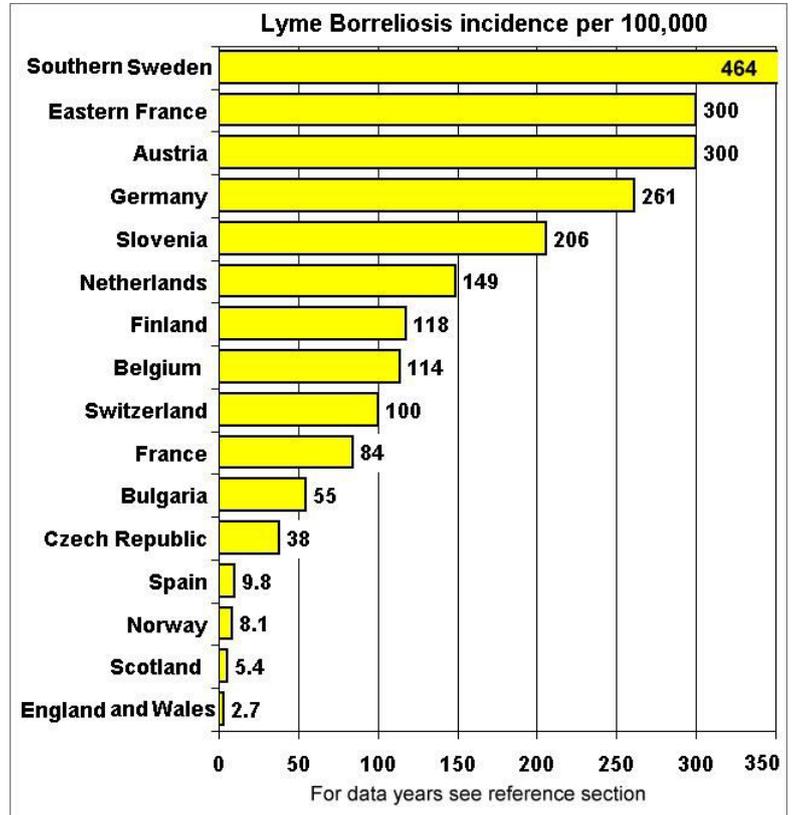


Estimating the Incidence of Lyme Borreliosis in England and Wales

According to Public Health England (PHE, 2018) the reported annual incidence for England and Wales in 2017 was 2.7 per 100k population, a 75% increase over 2010 figures. PHE's estimate that there are one or two thousand unreported cases, giving a maximum of 6.15 per 100k population. Yet neighbouring countries in continental Europe report many times more cases than even PHE's highest estimate:

France **14 x more cases**
Netherlands **24 x more cases**
Germany **42 x more cases**

Our neighbours are not only geographically close to the UK, they also have large regions with similar climate, geography, animals, birds and ticks.



Pfiefer (2016) observes: "In the Netherlands, rates of people diagnosed with the telltale Lyme rash ranged up to 514 per 100,000 in 2014. In areas of Germany and Sweden, studies of patient records found Lyme rates of 261 to 464 per 100,000. In Europe, the highest national rate—315 per 100,000 in 2009 – has been reported in Slovenia, one of few countries to aggressively track cases."

The following information is relevant when estimating the true incidence of Lyme borreliosis in England and Wales.

<1> PHE (2018) estimate that in addition to 'laboratory confirmed cases' there are one or two thousand unreported cases **[1.6X to 2.3X]**

<2> In 2007, the late Professor Klaus Kurtenbach of Bath University told the BBC, "In France they have diagnosed 10 times as many cases as here; yet we've found the same number of ticks here carrying the disease." (BBC. 2007) **[10X]**

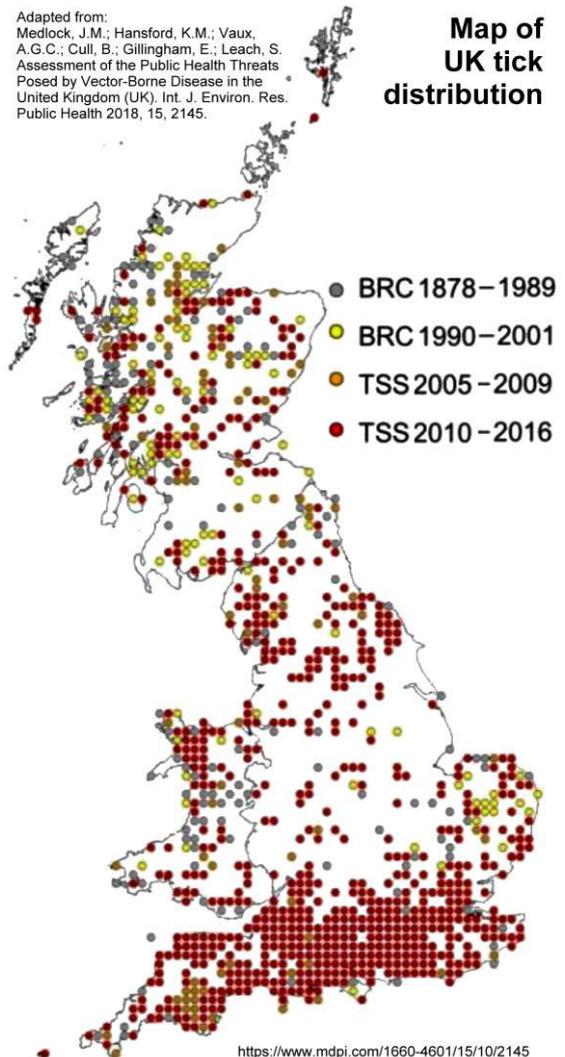
<3> Dr Darrel Ho-Yen, who was head of the Scottish Lyme Reference Laboratory at Inverness, was quoted in The Field (2005) magazine: 'He believes that the known number of proven cases should be multiplied by ten "to take account of wrongly-diagnosed cases, tests giving false results, sufferers who weren't tested, people who are infected but not showing symptoms, failures to notify and infected individuals who don't consult a doctor".' **[10X]**

<4> Bruce Alexander (2012) wrote in the Scotsman, "A recent audit of patients at a Perthshire Medical Practice found a ratio of confirmed cases equivalent to 125 per 100,000 people. Applying this ratio across Scotland, there could be around 6,500 people contracting Lyme disease each year, the vast majority going undiagnosed and untreated." This computes to 30 times the reported incidence for Scotland (2012 data), a country which has 3 times more recorded LB than England and Wales and where more doctors are alert to the risks and symptoms of LB. **[30X]**

<5> The CDC (2013) state: "The new estimate suggests that the total number of people diagnosed with Lyme disease is roughly 10 times higher than the yearly reported number. This new estimate supports studies published in the 1990s indicating that the true number of cases is between 3- and 12-fold higher than the number of reported cases." **[up to 12x]** And CDC (2015) states: "Researchers estimated that 288,000 (range 240,000–444,000) infections occur among patients for whom a laboratory specimen was submitted in 2008", and further add: "...based on medical claims information from a large insurance database. In this study, researchers estimated that 329,000 (range 296,000–376,000) cases of Lyme disease occur annually in the United States." **[>10x]**

<6> In England and Wales, in the 15 years from 1997 to 2011 there were a total of 7,903 cases of LB reported at an average of ~527 cases per annum giving an average annual incidence of ~0.93 per 100k population. (Public Health England. 2013.) This appearance of rarity has meant that most doctors are not alert to the risk of the disease, except perhaps in some LB 'hot-spots'.

(Picture: Distribution map of the ticks that carry Lyme borreliosis and which have been found in every county of England and Wales. From Int. J. Environ. Res. Public Health 2018, 15(10), 2145; <https://doi.org/10.3390/ijerph15102145>)



In 2016, patients provided quotes from their doctors which suggest that many UK doctors are not aware of how widespread Lyme borreliosis has become, which would predictably lead to many unrecognised and undiagnosed cases. Here are examples of what doctors have actually said to patients:

- Lyme disease does not exist in the UK
- There isn't any Lyme disease in Buckinghamshire. You can only get it in the New Forest and the Lake District in the UK
- In my twenty years of being a GP I have never seen a case of Lyme Disease
- There is no possibility whatsoever that you have Lyme disease, because it's quite rare
- You can't get Lyme disease in Scotland, there aren't even ticks at this time of year
- We don't have Lyme disease in Northamptonshire
- Lyme doesn't exist in Cornwall

- No Lyme or ticks in The South West of England
- UK ticks don't carry Lyme
- You can't have it, it's not like you have been deer hunting in Scotland.
- Well do you have deer in your garden?
- You cannot get Lyme disease in the UK
- The Americans need to keep their diseases to themselves. We don't have Lyme in the UK
- All your symptoms match Lyme. But that's rare
- I don't believe in Lyme
- You've not been out of the UK the child can't have Lyme
- You can't get it in the UK
- You can only get bitten by a tick if you go hill walking.

It is left to doctors to recognise and report Lyme borreliosis. Doctors misled by statistics which suggest that the disease is rare, and who are ill-informed about Lyme borreliosis, contribute to substantial under-detection and under-reporting. [??X]

<7> England's Lyme Reference Laboratory at RIPL, Porton Down, use tests that have not been validated for UK patients or the strains of LB found in the UK. Staff at the RIPL and the former HPA reference laboratory at Southampton have misleadingly informed doctors and patients that negative tests rule out a Lyme borreliosis diagnosis. PHE's incidence figures do not compensate for their use of unvalidated tests and false-negative results which could occur in around 50% of actual cases (according to the test kit manufacturer's figures). [??X]

<8> NHS Choices (2015) state: "Some people with Lyme disease also experience flu-like symptoms in the early stages, such as tiredness (fatigue), muscle pain, joint pain, headaches, a high temperature (fever), chills and neck stiffness. More serious symptoms may develop several weeks, months or even years later if Lyme disease is left untreated or is not treated early on." Infected patients often have varied and non-specific symptoms. If these are not recognised by either patient or doctor, then there is a significant risk that Lyme borreliosis will not even be considered as a potential diagnosis. This scenario could account for many undiagnosed and misdiagnosed UK Lyme cases. [??X]

CONCLUSION

The true incidence of Lyme in England and Wales will never be known until testing is reliable, doctors are alert to the risk and are provided with information that enables them to recognise potential cases, and patients consult a physician for symptoms correlating to Lyme. The PHE estimate of the true incidence in England and Wales is unrealistic. Comparing figures with neighbouring countries shows that there is a huge discrepancy. The public, GP's and even consultants in England and Wales are not equipped to recognise LB. PHE's claim to be 3 to 4 times more efficient at recording cases compared to USA authorities, with their 300,000+ annual cases, is insupportable.

Therefore VIRAS estimate that the minimum incidence of Lyme borreliosis in England and Wales is now between 15,000 and 45,000 new cases per year.

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