

PE1662/RR

Dr Anne Cruikshank submission of 23 November 2020

As a General Practitioner based in Oxfordshire, I have a long-standing interest in Lyme disease, ever since a close family member contracted the infection in 2007. I fully support this petition and am grateful for the opportunity to submit comments from a primary care perspective. I note the submissions from Professor John Lambert, with which I fully concur.

I have managed several hundred Lyme disease patients within NHS and military primary care settings, as well as within a specialist Lyme disease clinic led by Dr Matthew Dryden (lead microbiologist at the PHE Lyme Research Laboratory.)

In 2018 I was appointed as RCGP Clinical Champion for Lyme disease and led the RCGP Lyme disease Spotlight Project. The focus of this was to address the [NICE Lyme disease Guideline \(NG95\)](#) recommendation to 'raise awareness of the disease amongst both the medical profession and the general population'. The project was funded by charitable donations and ended in December 2019, following reorganisation within the RCGP.

The Spotlight team included GPs and Infectious diseases consultants with personal and professional experience of the disease. The key project outputs included the [RCGP Lyme disease Toolkit](#), GP workshops, and promotion of the RCGP/LDA Lyme disease e-learning module. (Two Scottish workshops had been envisaged for 2020.)

The toolkit provides a single point of access to relevant and accredited information, including multiple links to Health Protection Scotland. Both the toolkit and the e-learning module are endorsed by the NICE Quality Standard on Lyme disease. Unfortunately, neither were mentioned in the Chief Medical Officer's letter of June 2019.

UK-wide surveys revealed that the majority of GPs reported limited experience or confidence in providing advice on tick avoidance, managing tick bites or diagnosing and treating Lyme disease.

Improving patient outcomes

Prevention

Since 10-20% of Lyme disease infections result in persistent symptoms the health and financial implications for individuals and society as a whole are significant.

With concerted effort, a public health campaign could effectively raise the profile of Lyme disease. A significant amount of educational material is already available, via a range of government, NHS, local and patient-led organisations.

Heightened public awareness would result in better tick avoidance behaviour, early correct tick removal and early presentation to a primary care clinician should symptoms of Lyme disease develop. An asymptomatic skin rash or 'summer flu' will hold more significance for individuals who are 'lyme aware'.

Primary Care

Early Lyme disease must be considered to be a 'primary care illness', with patients likely to present to GPs, practice nurses and community pharmacists. Uncertainty regarding the features of an erythema migrans (EM) rash or the relevance of a test result regularly results in missed or mis-diagnoses. This despite clear NICE guidance that

- a) tick bites may go unnoticed,
- b) an EM rash, if present, is diagnostic,
- c) a negative test result does not exclude the diagnosis and
- d) antibiotic treatment may be instigated based on clinical suspicion.

Most GPs are unaware of the genuine scientific uncertainties and ongoing research in relation to both diagnosis and treatment of this disease. They struggle to know how best to support patients with persistent symptoms. Meanwhile their patients often access more detailed information from accredited sites such as the Lyme Resource Centre, Lyme disease Action and Lyme disease UK, leading to a discrepancy in understanding which then serves to undermine the doctor-patient relationship.

Since early diagnosis and treatment provide the best chance of cure, an educational programme aimed at developing 'Lyme Aware' primary care teams could reduce the incidence of late or missed diagnoses, thereby reducing the risk of chronic debilitating illness and potential medical litigation.

Secondary Care

The inexplicable climate of controversy and litigation that surrounds Lyme disease has resulted in a reluctance to develop expertise within secondary care. Clinicians frequently report a limited understanding of the disease whilst still insisting that "Chronic Lyme disease does not exist". Very few seem prepared to step outside of the restrictive NICE Guideline - despite the acknowledged poor-quality evidence upon which its recommendations are based. Those consultants who do attempt to follow non-UK guidelines are frequently disparaged by colleagues.

Significant progress could be achieved by the establishment of a Scottish multidisciplinary treatment service for the evaluation, support and management of patients with chronic and persistent symptoms of tick-borne infections

Meeting the challenge

Improving patient outcomes in relation to tick-borne diseases will require considerable commitment. Some aspects of the process could be initiated with relative ease, whilst others will take longer.

However, consideration of all that has been learnt and achieved during the present pandemic, highlights the certainty that, with team work, education, scientific curiosity and empathy, this challenge is not insurmountable.