

# Lyme borreliosis in the UK compared with Europe: the *differences* and why they may matter

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Mainland Europe	UK	Consequence
<b>First cases</b>		
Erythema chronicum migrans known for more than 100 years	First confirmed case 1979 <sup>1</sup>	UK seroprevalence probably lower than in Europe; only Scotland known with regional variation of 0-8.6% <sup>2</sup> .  Useful population for assessing test sensitivity?
<b>Incidence</b>		
NorthTick region: 22-50 /100,000	UK: 3-13 /100,000	UK cases scattered thinly across the country.  Public & clinicians less aware
<b>Time to diagnosis</b>		
Comparable data is lacking but estimates from studies reporting EM and disseminated cases: Hofhuis et al 2015 - disseminated LB - <b>5.5%</b> Ursinus et al 2021 - disseminated - <b>5.1%</b> Geebelen et al 2021 - disseminated - <b>5.7%</b>	UK: only +ve serology reported. Study of GP records <sup>3</sup> estimates incidence 2.35 times reported figures. If we assume the extra are EM diagnosed without serology, England & Wales estimate is <b>43% disseminated</b> , of which 30% are longstanding <sup>4</sup> . Scotland reports less detail.	More late diagnoses
<b>The most prevalent Borrelia genospecies in Ticks</b>		
<i>Borrelia afzelii</i>	Scotland: <i>Borrelia afzelii</i> <sup>5,6</sup> Scottish islands: <i>Borrelia garinii</i> <sup>7</sup> England: <i>Borrelia garinii</i> <sup>8,9</sup>	Ticks in England and Scottish Islands predominantly carry more <i>B garinii</i> , though there is no information on the cause of human infections.  Different LB More LNB
<b>LB specialist clinics</b>		
Norway, Netherlands, Denmark, France and others.	None	<ul style="list-style-type: none"> <li>No opportunity for health professionals to gain experience.</li> <li>No opportunity for patients with complex presentations to be considered by experienced clinicians.</li> </ul>
<b>Trials, cohort studies</b>		
Numerous	Few	Recommendations on treatment for UK patients are derived from European research on European patients with a relatively short duration of illness.
<b>Clinicians with experience</b>		
<b>Many well informed</b> in both primary and secondary care. Most know that LB can cause a variety of presentations, including (albeit very rarely) endocarditis.	<b>Very few</b> well informed; <b>none</b> with significant experience; <b>none</b> with apparent interest.	<ul style="list-style-type: none"> <li>UK clinicians believe the conclusions from European studies that most patients recover.</li> <li>A clinician advising the national reference laboratory wrote in 2022</li> </ul> <p style="text-align: center;">"Lyme does not cause endocarditis"</p>

## Conclusions

The UK appears to have a different cohort of patients from those in European studies. While there may be insufficient patients for a UK specific trial to gain significance, including UK patients in a European study may well shed more light on

- Late Lyme borreliosis
- Disseminated non-specific Lyme borreliosis
- Continuing symptoms following treatment

Studies including UK patients could help patients and clinicians everywhere.

## Challenges to address the unmet needs of late diagnosed patients and their clinicians

Longer term follow up?

- UK specialist clinic to:
- Study complex cases
  - Give clinicians experience

Core Outcome Set designed by both patients and clinicians?

Persistent symptoms: Biomarkers?  
Autoantibodies? Genomics?  
**If you don't look, you won't find.**

International collaboration?

Include patients in study design?

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