



An insight into ticks & Lyme disease in Scotland

1st May 2024, LRC Event, Scottish Parliament, Holyrood

In recent years, Scotland has taken significant steps to increase awareness of ticks and Lyme disease, including the well received pharmacy poster tick awareness campaigns. However, *the* recent Lyme Resource Centre (LRC) survey clearly demonstrates more action is needed in raising awareness with the public and health professionals, to reduce suffering and prevent life-changing consequences of Lyme disease in Scotland.

About Lyme Disease

Lyme disease is an infection caused by the bacteria *Borrelia burgdorferi*, passed to humans by the bite of an infected tick. Studies indicate that the annual number of new infections is increasing and likely to be higher than official estimates ([Incidence of Lyme disease in UK: BMJ Open](#)).

With prompt diagnosis and treatment, many people make a full recovery, whilst others remain ill even after antibiotic treatment.

Lack of formally documented evidence about the lived experience of people with Lyme disease and their long-term clinical and social outcomes has been a barrier to acknowledging and understanding ‘on the ground’ realities. This has impaired much needed improvements in diagnosis, treatment and care.

Key Points from Tonight’s Event

- Ticks and tick-borne diseases are a **growing problem** across Scotland
- **More education** to make the public tick aware will enable safe enjoyment of outdoors
- **Early recognition & effective treatment** of Lyme disease is essential to prevent long term health and life consequences
- Increased **awareness amongst health professionals** is required to improve health outcomes

Action - People with Lyme Disease Need Your Help

Scotland would benefit from

- an active, targeted public health approach to further raise awareness of ticks and Lyme disease amongst both the public and health professionals
- identifying and tackling why people with Lyme disease are not being diagnosed early
- reviewing treatment guidelines
- supporting better health and life outcomes for patients

Please help combat the risk from Lyme disease

About LRC

Lyme Resource Centre (LRC) is an independent Scottish Charity, with a mission to educate the public and health professionals about Lyme disease and other tick-borne illnesses. Visit the [LRC website](#) to access our resources or contact the LRC Team for further information & expertise via admin@lymeresourcecentre.com



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LRC Lyme Disease Experience Survey

In February 2024 LRC launched the Lyme Disease Experience Survey in UK and Republic of Ireland, to explore awareness of ticks and Lyme disease and capture the lived experiences of people affected by Lyme disease, including diagnosis, treatment and health outcomes.

The survey aims to drive meaningful change for people who contract and live with Lyme disease and its consequences. The survey sought to capture responses from people who had fully recovered from Lyme disease as well as those with ongoing symptoms. The following page shows *preliminary* key findings for Scotland.

Challenges of Lyme Disease

- True case numbers of Lyme disease are unknown (UKHSA)
- Public and health professional awareness of ticks and Lyme disease remains inadequate
- Tick bites are painless and can easily go unnoticed
- Lyme disease is a complex illness and can be difficult to diagnose
- Lyme disease testing can be unreliable
- Standard treatment protocols may not always be effective
- The causes of persistent symptoms are not well understood

Current UK Guidance

[NICE | Lyme disease | guidance](#) (NG95) 2018, aims to raise awareness of when Lyme disease should be suspected and supports health professionals in providing prompt and consistent diagnosis and treatment. The NICE guidance acknowledges its limitations, including:

- There is a lack of epidemiological data on the incidence, clinical features, management and outcome of Lyme disease in the UK.
- The guideline committee has noted the poor-quality evidence available on both diagnosis and treatment.
- The evidence on the effectiveness of antimicrobial treatment regimens used in different presentations of Lyme disease is of poor quality, out-dated and often based on small studies.

It should be noted that there is no international consensus on the required duration of treatment or on the causes and management of persistent symptoms.

“Skeptics beat their chests about evidence-based medicine and never grapple with what patients should do when medicine doesn’t bother to create an evidence base for your condition’.” Ed Yong (Science Reporter, Pulitzer Prize Winner)

“Lyme disease is where cancer was 40 years ago.. . Why are we always starting from scratch?” Neil Spector MD



Key Findings

This initial analysis is based on the 108 responses from participants, resident in Scotland, who reported a diagnosis of Lyme disease confirmed by a qualified healthcare professional; key findings are summarised below. Further findings are available in subsequent page(s) of this document.

Awareness

- 34% unaware of need to protect against tick bites prior to being unwell
- 42% unaware of Lyme disease prior to becoming unwell

"I recalled having a Lyme rash a few days after the bite but I didn't know what it was."

The survey reveals a lack of public awareness on how to prevent and manage tick bites, and when to seek help.

Scotland must prioritise raising awareness of tick bites and Lyme disease

Diagnosis

- 74% were not diagnosed within 4 weeks of onset of symptoms
- 31% were not diagnosed for over a year after onset of symptoms

"First doctor I visited...told me he had never seen a Lyme disease case, it was just a random virus."

Survey responses show serious delays in diagnosis - yet early diagnosis and prompt treatment is known to provide the best chance of recovery.

Timely diagnosis of Lyme disease in Scotland must improve

Treatment

- 70% had difficulty accessing treatment
- 45% did not receive antibiotics within 3 months of onset of symptoms
- 78% did not fully recover after one course of antibiotics

"The gaslighting I've encountered at the Doctors has been horrifically traumatic."

The survey revealed problems in accessing prompt and effective treatment.

Prompt, effective treatment for Lyme disease must be available across Scotland

Ongoing Needs

- 73% have ongoing symptoms related to Lyme disease
- 56% have been unwell for more than 2 years
- 50% reported financial impact due to loss of income, treatment costs
- 31% reported loss of independence

"I was fiercely independent and strong before, now I'm vulnerable ...I lost career, family, friends, income, independence.."

Many respondents report chronic ill health with life-changing impact as a result of Lyme disease infection.

Scotland must meet the needs of those with ongoing consequences of Lyme disease

"In the fullness of time, the mainstream handling of Chronic Lyme disease will be viewed as one of the most shameful episodes in the history of medicine...."

Kenneth B. Liegner, M.D



LRC Lyme Disease Experience Survey

Survey Method

In researching the approach to the survey LRC consulted with the CEO of [MyLymeData](#), a USA based, patient-powered research project with significant experience in surveys for Lyme disease.

Survey Monkey was chosen as the platform for an online survey due to its ease of use, functionality, and cost effectiveness. To avoid concerns over data privacy and to encourage open, honest responses, the survey was conducted anonymously.

Participants were recruited via

- open invitation on the LRC website
- social media channels (Facebook, Instagram, LinkedIn, X [Twitter])
- other organisations including Lyme Disease UK, TickTalk Ireland, Lyme Disease Alba, and others who shared and promoted the survey
- organisations whose members or followers use the outdoors professionally, educationally or socially (e.g. National Farmers Union, Forest Schools Association, Ramblers Association)
- individuals, who raised awareness of the survey with their own networks.

Survey Respondents

There were 472 completed responses from UK and Republic of Ireland between 1st February 2024 and 3rd April 2024**, of which 108 were were resident in Scotland **and who also reported a diagnosis of Lyme disease confirmed by a qualified health professional**. Participation in the survey was voluntary and anonymous.

Respondents were asked to confirm their answers were accurate to the best of their knowledge prior to submitting their survey response. The large number of completed responses from the UK and Republic of Ireland (almost 500) should minimise the impact of any response inaccuracies.

There was no direct access to patients themselves or to any medical records. Individuals who could **not** report a diagnosis of Lyme disease by a qualified health professional (including self-diagnosis) were excluded.

We are mindful that some people who fully recovered from Lyme disease may have been unaware of the survey - we aimed to address this by promoting the survey via outdoor organisations. People with undiagnosed Lyme disease are not represented in this survey.

Acknowledgements

We would like to give our heartfelt thanks to all survey respondents for their time and for sharing their experiences openly and honestly. We would like to thank the Lyme disease charities across UK and Ireland, and other organisations for promoting the survey and to the individuals who helped promote the survey on social media and word of mouth.

The survey authors confirm no conflicts of interest.

**Note that the survey is ongoing at the time of writing.