



Little is formally documented on the lived experience of Lyme disease - the state of diagnosis, treatment & care and the impact on the lives of those infected. *Lyme Resource Centre (LRC) conducted an online survey to gather information on the impact of Lyme disease in the United Kingdom & Republic of Ireland.*

**NICE** National Institute for Health and Care Excellence

Application of key NICE Guideline 95 directions for diagnosis and treatment of Lyme disease

**NICE Guideline 95 covers diagnosing and managing Lyme disease. It aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment. It does not cover preventing Lyme disease.**



<b>DIAGNOSIS</b>	<b>1.2.1 Diagnose Lyme disease in people with erythema migrans</b>	<b>1.2.11 Diagnose and treat Lyme disease without laboratory testing in people with erythema migrans</b>	
	<i>100 respondents were diagnosed with Lyme disease by NHS clinicians; 66 diagnosed by GP</i>		
	71 respondents described having an erythema migrans (EM); 46 described typical bull's eye	50 respondents with EM also had Lyme disease blood test; 37 positive	73 of 100 (73%) had Lyme disease blood test; 48 tests were positive

<b>TREATMENT - 1</b>	<b>1.3.4 / 1.3.5 Offer antibiotic treatment according to symptoms as described [in Table 1 in NG95]</b>			
	<i>99 respondents diagnosed with Lyme disease by NHS clinicians were prescribed antibiotics</i>			
	<b>First Antibiotics:</b> Doxycycline – 74 Amoxicillin – 11 Ceftriaxone IV - 1 Other antibiotics - 13	<b>39</b> of these 99 respondents did not get antibiotics within 4 weeks of symptoms	Duration of first antibiotics (No. respondents): <b>21 days or more = 81</b> <b>less than 21 days = 18</b>	First antibiotics prescribed by <b>GP = 81</b>

<b>TREATMENT - 2</b>	<b>1.3.11 Consider a second course of antibiotics for people with ongoing symptoms</b>	<b>1.3.1. Use an alternative antibiotic to the initial course</b>	
	<i>77 respondents did not fully recover after first antibiotics</i>		
	49 respondents were prescribed further antibiotics	Did not fully recover after first antibiotics but <b>did not get 2<sup>nd</sup> antibiotics</b> – 30 respondents	Had same antibiotic prescribed second time – 14 respondents

<b>OUTCOME</b>	<b>1.4.1 prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery</b>	<b>1.3.17 Support people who have ongoing symptoms after treatment for Lyme disease</b>	
	Of 99 respondents who got antibiotics, <b>22 fully recovered after first antibiotics</b>	Of 99 respondents who got antibiotics, <b>just 26 (now) fully recovered</b>	Of 99 respondents who got antibiotics, <b>73 not (now) fully recovered from Lyme disease</b>

## About Lyme Resource Centre (LRC)

Lyme Resource Centre is a Scottish registered charity (SCIO: SC049151) focused on educating the public and healthcare professionals about Lyme disease & other tick-borne illnesses

<https://www.lymeresourcecentre.com>

## About the Survey

From 1<sup>st</sup> February to 30<sup>th</sup> April 2024, LRC ran a **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 sought to capture responses from people who had fully recovered from Lyme disease as well as those with ongoing symptoms and aimed to drive meaningful change for people who contract and live with Lyme disease and its consequences.

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 and patient data collection for Lyme disease.

Survey Monkey was chosen as the platform for an online survey due to its ease of use, functionality, and cost effectiveness.

## Survey Method

To avoid concerns over data privacy and to encourage open, honest responses, the survey was conducted anonymously and participation was voluntary.

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

Out of 491 completed responses from UK and Republic of Ireland between 1st February 2024 and 30<sup>th</sup> April 2024, **475 reported a diagnosis of Lyme disease confirmed by a qualified health professional; 311 of these responses were from residents of UK and form the basis of this analysis.** Respondents who could **not** report a diagnosis of Lyme disease by a qualified health professional (including self-diagnosis) were excluded.

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 (almost 500) should minimise the impact of any response inaccuracies.

There was no direct access to patients themselves or to any medical records.

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.

## References

- NICE Guideline [NG95] Lyme Disease <https://www.nice.org.uk/guideline/ng95>
- UKHSA *Lyme disease: Management and Prevention* <https://www.gov.uk/guidance/lyme-disease-management-and-prevention>