Lyme Disease Experience Survey – Infected 18 & Under

LRC
LYME RESOURCE CENTRE

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.***

90 of 475 respondents aged 18 yrs or under when Lyme disease symptoms began *and* who also reported being diagnosed with Lyme disease by qualified health professional; these responses used for this analysis

AWARENESS

NICE evidence review highlights '*Raising awareness of Lyme disease reduces the possibility that people with Lyme disease are overlooked or not adequately assessed and diagnosed for Lyme disease.*'

Age when bitten	
6-11 yrs	12-18 yrs
42%	**52%**

33% bitten when walking / running, camping or on educational trip

33% don't recall a tick bite or not sure

77% were not aware of need to protect against tick bites prior to illness

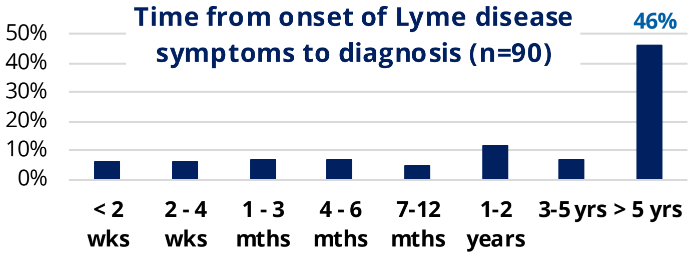
78% were not aware of signs, symptoms of Lyme disease prior to illness

Raising awareness of tick bites and Lyme disease is a priority

DIAGNOSIS

NICE guideline *"aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment".*

53% respondents had an Erythema Migrans (EM) rash



Time from onset of Lyme disease symptoms to diagnosis (n=90)

From onset of symptoms

89% not diagnosed **within 4 weeks**

82% **not diagnosed** within 3 months

71% **not diagnosed** for > one year

Timely diagnosis of Lyme disease must improve

TREATMENT

NICE guideline states '*Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery".*

91% had difficulty accessing treatment

10% did not receive antibiotics

Of the 90% who had antibiotics

11% **received first antibiotic within 4 weeks** and

20% **within 3 months**

68% **delay of over a year to first antibiotic**, and

35% **delay of 2 years or more**

93% **did not fully recover** after first antibiotic

Prompt, effective treatment for Lyme disease must be available

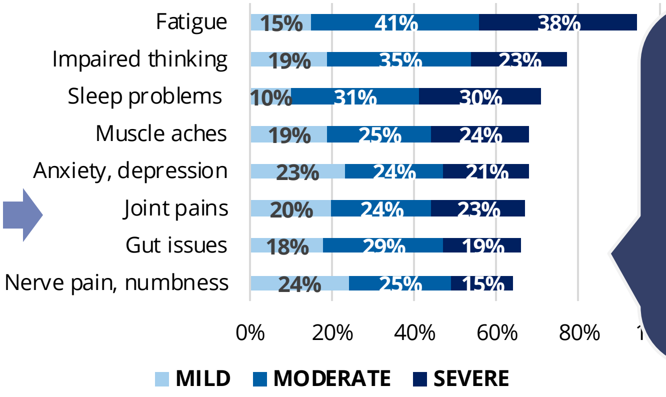
ONGOING NEEDS

NICE guideline states '*Symptoms can be more severe and long-lasting if treatment is delayed*'.

89% have ongoing symptoms

68% been unwell for **6+ years**

Most commonly reported ongoing symptoms (n=80)



> ***"I had to leave school and am not able to work. It has impacted and interfered with every part of my life. I have no social life no friends and no prospects. Lyme has destroyed my life."***

The needs of those with ongoing consequences of Lyme disease must be met

SOURCE: LRC Lyme Disease Experience Survey, 2024
Online survey exploring experience of Lyme disease – United Kingdom & Rep. of Ireland; February to April 2024
Data based on respondents diagnosed with Lyme disease by qualified health professional

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AWARENESS - Raising awareness of tick bites and Lyme disease is a priority

NICE evidence review highlights '*Raising awareness of Lyme disease reduces the possibility that people with Lyme disease are overlooked or not adequately assessed and diagnosed for Lyme disease.*"

SURVEY HIGHLIGHTS A SIGNIFICANT AWARENESS GAP

90 of 475 respondents aged 18 yrs or under when Lyme disease symptoms began *and* who also reported being diagnosed with Lyme disease by qualified health professional; these responses used for this analysis

Age when symptoms started

6-11 yrs	12-18 yrs
42%	**52%**

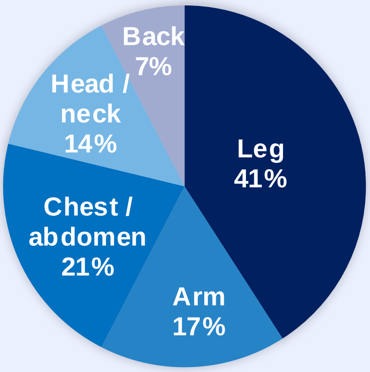
33% bitten when walking / running, camping or on educational trip

33% don't recall a tick bite or not sure

77% **not aware** of need to protect against **tick bites** prior to illness

not aware of signs, symptoms of **Lyme disease** prior to illness **78%**

Where on your body was the tick bite (all mentions)



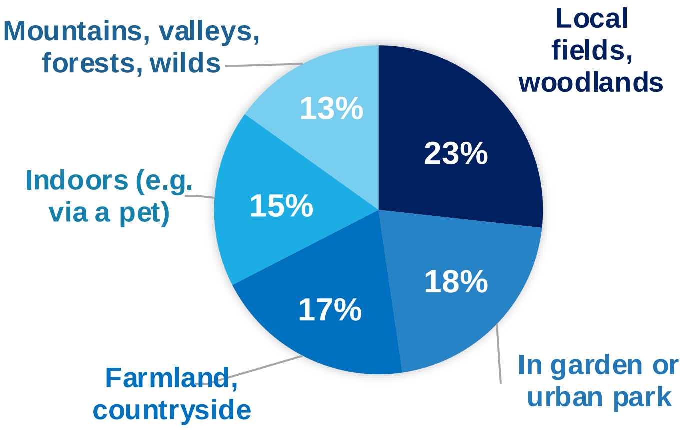
"Better awareness amongst health professionals"

"Health professionals who understood and recognised Lyme disease ."

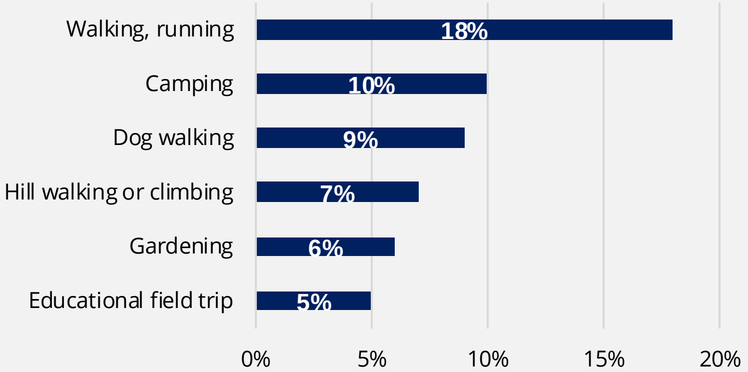
What could have been better during your illness and recovery?

Tick bites occur in everyday places

Top locations when bites occurred (all mentions)



Top activities when tick bites occurred (all mentions)



55% bites happened in England, Scotland & ROI

18% uncertain where they were bitten

16% bitten overseas including –

Austria, Belgium, Canada, Denmark, France, Greece, China, Italy, Luxembourg, Netherlands, Portugal, Slovakia, Spain, USA

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DIAGNOSIS - Timely diagnosis of Lyme disease must improve

NICE guideline *"aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment".*

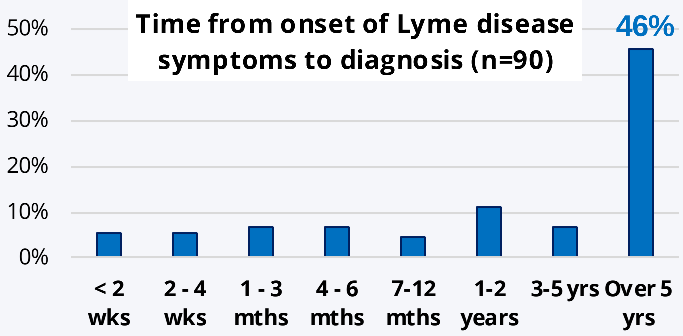
SURVEY HIGHLIGHTS MISSED OPPORTUNITIES FOR DIAGNOSIS

90 of 475

respondents aged 18 yrs or under when Lyme disease symptoms began *and* who also reported being diagnosed with Lyme disease by qualified health professional; these responses used for this analysis

53%

respondents had an Erythema Migrans (EM) rash



From onset of symptoms

89%
not diagnosed within 4 weeks

82%
not diagnosed within 3 months

71%
not diagnosed for > one year

for **60%** respondents, diagnosis of Lyme disease was first suspected by self, family, friends or colleagues

Diagnosis of Lyme disease made by **GP**

25%
respondents -

73%
diagnosed by secondary care

> *"(my) diagnosis took 23 years ."*

11
different recognised secondary care medical specialties made **diagnosis of Lyme disease**

Average
43
estimated **visits to GP** with Lyme related symptoms (n=88)

19
different medical specialties involved with respondents' Lyme related symptoms

52%
attended A&E with Lyme related symptoms (n=89)

Just
2%
respondents diagnosed by an allied health professional

> ***"…didn't initially take my diagnosis seriously ….despite bullseye rash and symptoms."***

80+
different medical conditions suggested or diagnosed before Lyme disease diagnosis
(n=78, all mentions)

> ***"….took months for referral to paediatrics, and then still said it isn't Lyme, even with a positive (test) result."***

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TREATMENT - Prompt, effective treatment for Lyme disease must be available

NICE guideline states '*Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery".*

SURVEY HIGHLIGHTS MISSED OPPORTUNITIES FOR TREATMENT

90 of 475 respondents aged 18 yrs or under when Lyme disease symptoms began *and* who also reported being diagnosed with Lyme disease by qualified health professional; these responses used for this analysis

90%
had antibiotics

91%
had difficulty accessing treatment

Of the 90% who had antibiotics

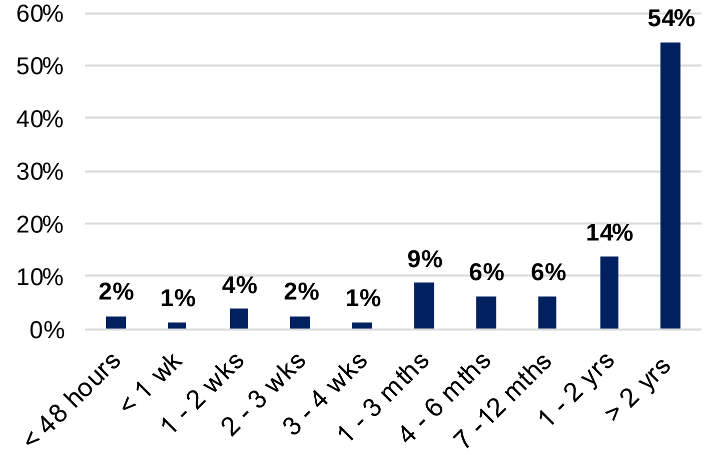
11%
received first antibiotic within 4 weeks and

20%
within 3 months

46%
had delay of over a year to first antibiotic, and

54%
had delay of 2 years or more

93%
did not fully recover after first antibiotic



Time from symptoms to first antibiotic (n=81)

Of 54% who had delay of > 2 years from symptoms to first antibiotic, average length of delay was
19 yrs

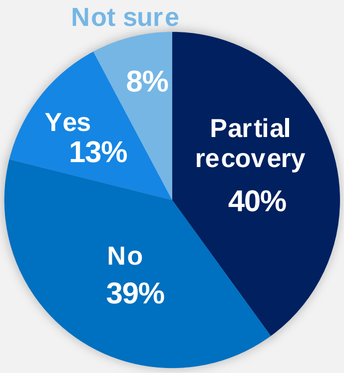
31%
did not get second antibiotic

93%
have been unwell with Lyme disease for
a year or more

> ***"Misdiagnosis and ineffective treatment have had a pervasive impact on every aspect of my life."***

Just 13%
have recovered from Lyme disease

Have you now recovered from Lyme disease?



79%
have **not fully recovered** from Lyme disease

Of 91% who had difficulty accessing treatment

98%
say **lack of disease awareness & expertise amongst health professionals** is **top barrier** to treatment followed by **misdiagnosis**

Key reasons for difficulty accessing treatment (N=83) [all mentions]

Lack of disease awareness / expertise of health professionals	98%
Misdiagnosis resulting in delayed diagnosis & treatment	83%
Diagnosis excluded due to negative / inconclusive blood test* (*despite Lyme symptoms)	61%
Cost of private treatment	59%
Stigma associated with Lyme disease	57%
Restrictive treatment guidelines	54%

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ONGOING NEEDS - of those with consequences of Lyme disease must be met

NICE guideline states *'Symptoms can be more severe and long-lasting if treatment is delayed'.*

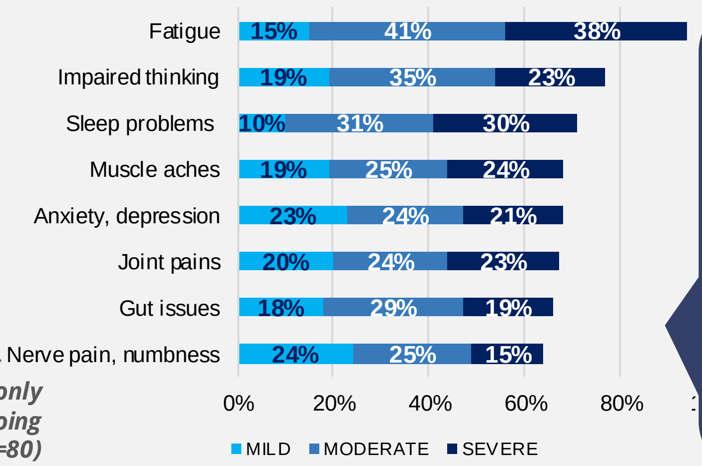
SURVEY SUGGESTS SIGNIFICANT ONGOING NEEDS FOR MANY WITH LYME DISEASE

90 of 475 respondents aged 18 yrs or under when Lyme disease symptoms began *and* who also reported being diagnosed with Lyme disease by qualified health professional; these responses used for this analysis

79% have **not fully recovered** from Lyme disease

89% have ongoing symptoms

68% have been unwell for **6+ years**



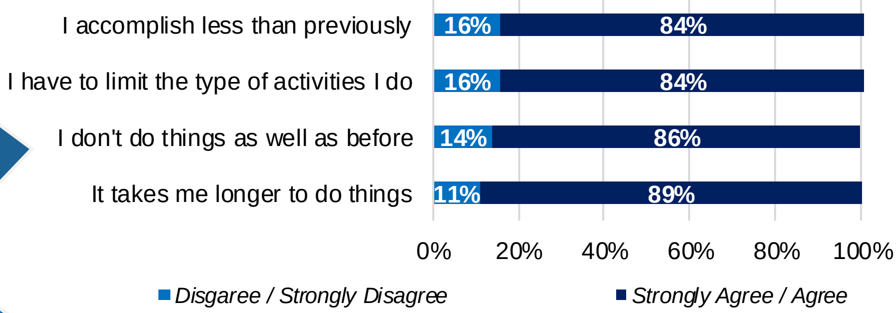
Most commonly reported ongoing symptoms (n=80)

> ***"(My son's) life has been put on hold due to Lyme. He doesn't leave the house. Didn't complete his school education and doesn't have any friends due to his health."***

> ***"I had to leave school and am not able to work. It has impacted and interfered with every part of my life. I have no social life no friends and no prospects. Lyme has destroyed my life."***

> ***"Lyme continues to affect my daughter's life on a day to day basis, she is part-time at school, has chronic fatigue and feels frequently unwell as a result."***

How has Lyme disease affected your day to day functioning (n=90)



86%

Strongly Agree or Agree that Lyme disease has affected day-to-day functioning

> ***"It it has had such a huge impact on my life, from early years through adulthood."***

Has Lyme disease affected you in other ways? (n=90)

[all mentions]

Affected social life and hobbies	92%
Affected relationships with family, friends	81%
Financial loss	74%
Stigma associated with Lyme disease	68%
Educational consequences	67%
Career consequences	64%
Loss of independence	60%

> ***"…I wake each day feeling just as exhausted as when I fell into bed……. I can plan nothing, I lost a glittering career, all of my social circle, my self respect, the respect of others, and all joy. It has been devastating, like a stolen life."***

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About Lyme Resource Centre (LRC)

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

About the Survey

From 1st February to 30th 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 the survey due to 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 personal networks.

Survey Respondents

Out of 491 completed responses between 1st February 2024 and 30th April 2024, *475 reported a diagnosis of Lyme disease confirmed by a qualified health professional*. ***Ninety (90) of these respondents were 18 years or under when symptoms of Lyme disease began 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
- *HSE Expert Advisory Committee - Antibiotic Prescribing - Lyme disease* https://www.hse.ie/eng/services/list/2/gp/antibiotic-prescribing/conditions-and-treatments/skin-soft-tissue/lyme-disease/
- HSE HPSC advises - Be tick aware, keep you and your family safe from Lyme disease, May 2024 https://about.hse.ie/news/hse-hpsc-advises-be-tick-aware-keep-you-and-your-family-safe-from-lyme-disease/