

Lyme Disease Experience Survey - All Responses

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.

AWARENESS

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

HSE Health Protection Surveillance Centre (HPSC) offers practical advice on how to protect against ticks & prevent Lyme disease

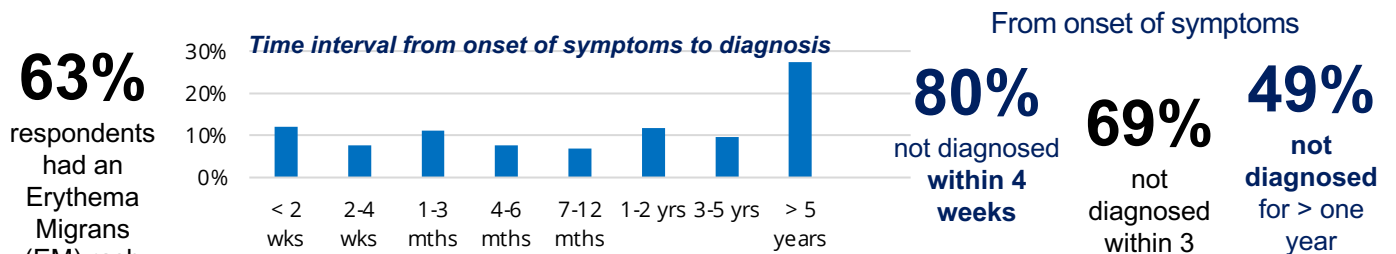


Raising awareness of tick bites and Lyme disease is a priority

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"*.

HSE Expert Advisory Committee advises early identification of Lyme disease to minimise likelihood of late stage infection.



Timely diagnosis of Lyme disease must improve

TREATMENT

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

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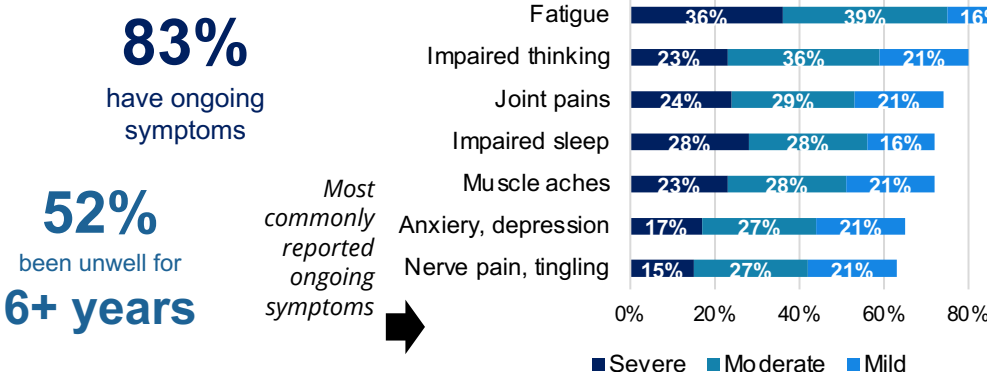


Prompt, effective treatment for Lyme disease must be available

ONGOING NEEDS

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

HSE Expert Advisory Committee advises prompt and appropriate antibiotic therapy to minimise likelihood oflong term complications of Lyme disease.



"I was fiercely independent and strong before, now I'm vulnerable and rely on others good will and love. I lost career, family, friends, income, independence. It's hard to do anything now.....I wouldn't wish this on anyone."

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

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SURVEY HIGHLIGHTS A SIGNIFICANT AWARENESS GAP

475

reported a diagnosis of Lyme disease confirmed by qualified health professional

26%

were bitten in an urban park, garden or indoors (via pet)

41%

don't recall a tick bite or not sure

64%

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

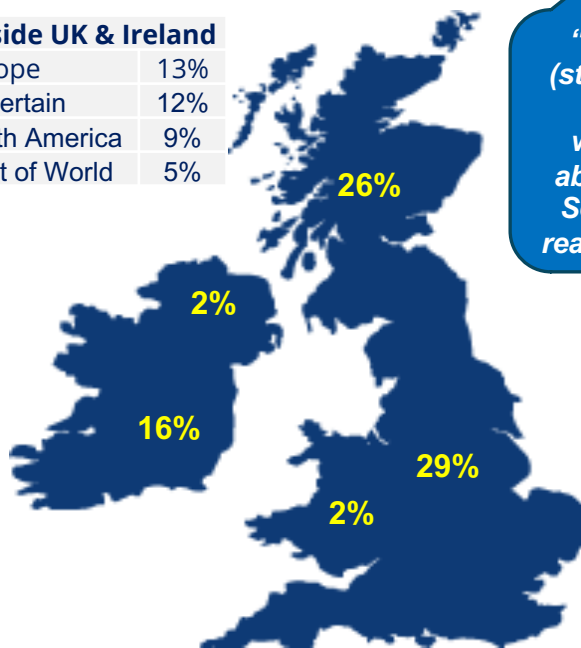
69%

were not aware of Lyme disease prior to illness

Where bitten (all mentions)

Outside UK & Ireland

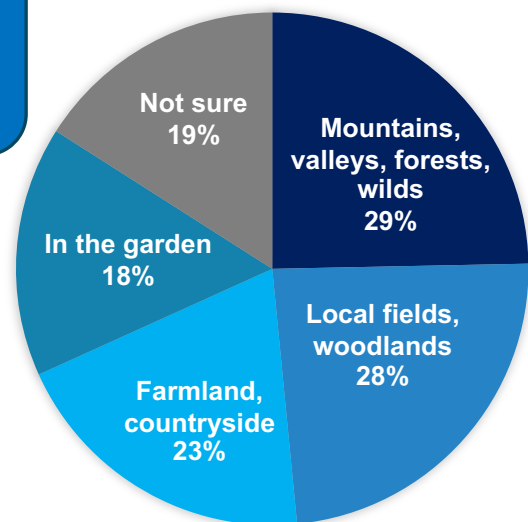
Europe	13%
Uncertain	12%
North America	9%
Rest of World	5%



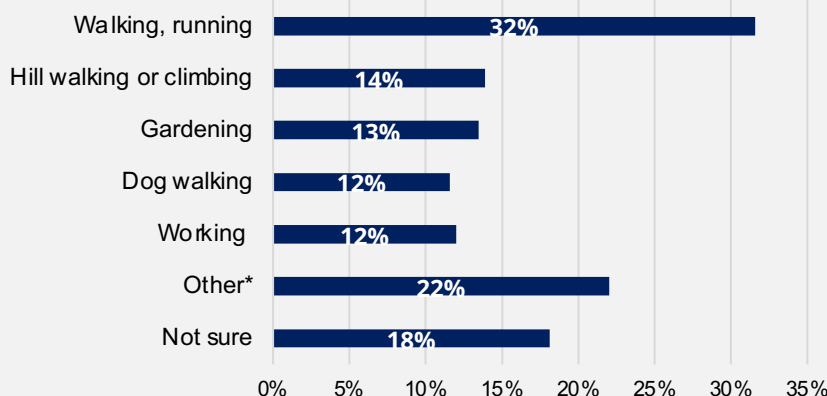
“.....there (still) are too little warnings about ticks! So I wasn't really aware.”

Tick bites occur in everyday places

Top 5 locations when bitten



Top activities when tick bites occurred



70%

bites happened in England, Scotland & ROI

12%

uncertain where they were bitten

Of those who found and removed a tick, only

23%

used a recognised tick removal tool

*Other - examples include horse-related, foraging, bird-watching, fishing, playing outdoors

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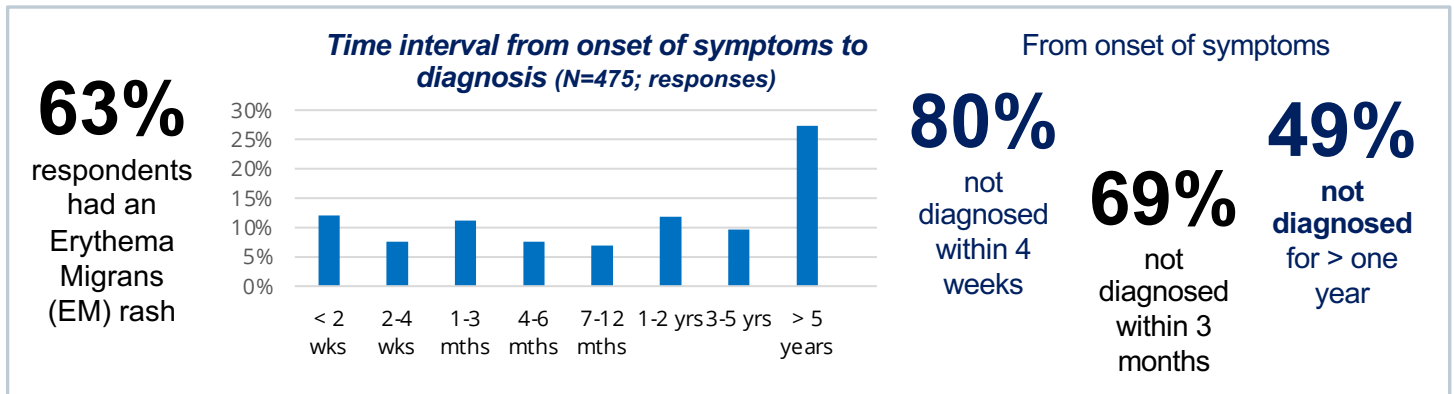
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SURVEY HIGHLIGHTS MISSED OPPORTUNITIES FOR DIAGNOSIS



for **76%** respondents, diagnosis of Lyme disease was first suspected by self, family, friends or colleagues

Diagnosis of Lyme disease made by GP for **40%** respondents - remainder diagnosed in secondary care

“GP didn’t initially take my diagnosis seriously....”

16 different recognised secondary care medical specialties made diagnosis of Lyme disease

Average **26** estimated visits to GP with Lyme related symptoms (N=471)

>20 different medical specialties involved with respondents’ Lyme related symptoms

51% attended A&E with Lyme related symptoms (N=472)

Just **3%** respondents diagnosed by an allied health professional

“Diagnosis was extremely difficult – it took nearly 3 years.”

90+ different medical conditions suggested or diagnosed before Lyme disease diagnosis

“Lack of correct diagnosis early on led me to suffering immensely for many years.”

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SURVEY HIGHLIGHTS MISSED OPORTUNITIES FOR TREATMENT

90%
had antibiotics

83%
had difficulty accessing treatment

Of the 90% who had antibiotics

28%
received first antibiotic within 4 weeks and

38%
within 3 months

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

35%
had delay of 2 years or more

86%
did not fully recover after first antibiotic

Time from symptoms to first antibiotic (n=429)

Time Interval	Percentage
< 48 hrs	~5%
< 1 wk	~5%
1-2 wks	~5%
2-3 wks	~5%
3-4 wks	~5%
1-3 mths	~10%
4-6 mths	~10%
7-12 mths	~10%
1-2 yrs	~10%
> 2 yrs	~35%

Of 35% who had delay of > 2 years from symptoms to first antibiotic, average length of delay was

12 yrs

81% 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."

"Untreated LD pushed me into needing to die but desperate to live."

Just 18% have recovered from Lyme disease

Have you now recovered from Lyme disease?

82% have not fully recovered from Lyme disease

Of 83% who had difficulty accessing treatment

78% say lack of disease awareness & expertise amongst health professionals is top barrier to treatment followed by misdiagnosis

Key reasons for difficulty accessing treatment (N=408)	
Lack of disease awareness / expertise of health professionals	90%
Misdiagnosis resulting in delayed diagnosis & treatment	68%
Diagnosis excluded due to negative / inconclusive blood test*	54%
Cost of private treatment (*despite Lyme symptoms)	52%
Restrictive treatment guidelines	48%
Stigma associated with Lyme disease	42%

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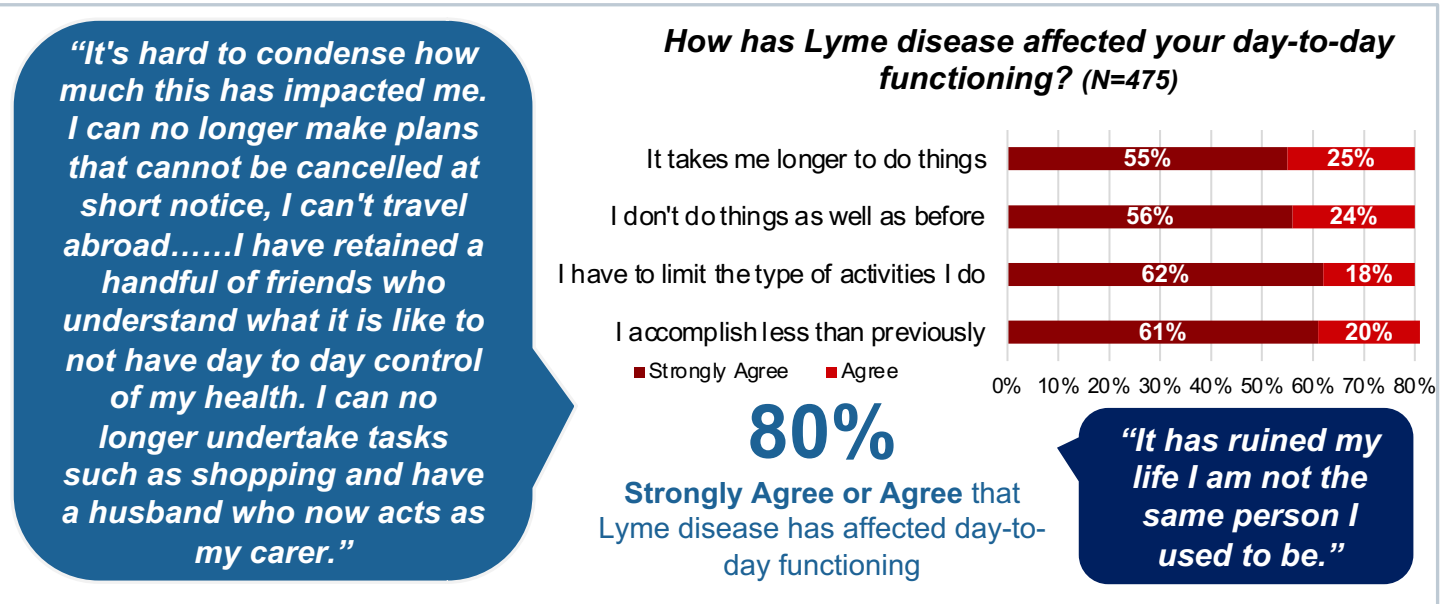
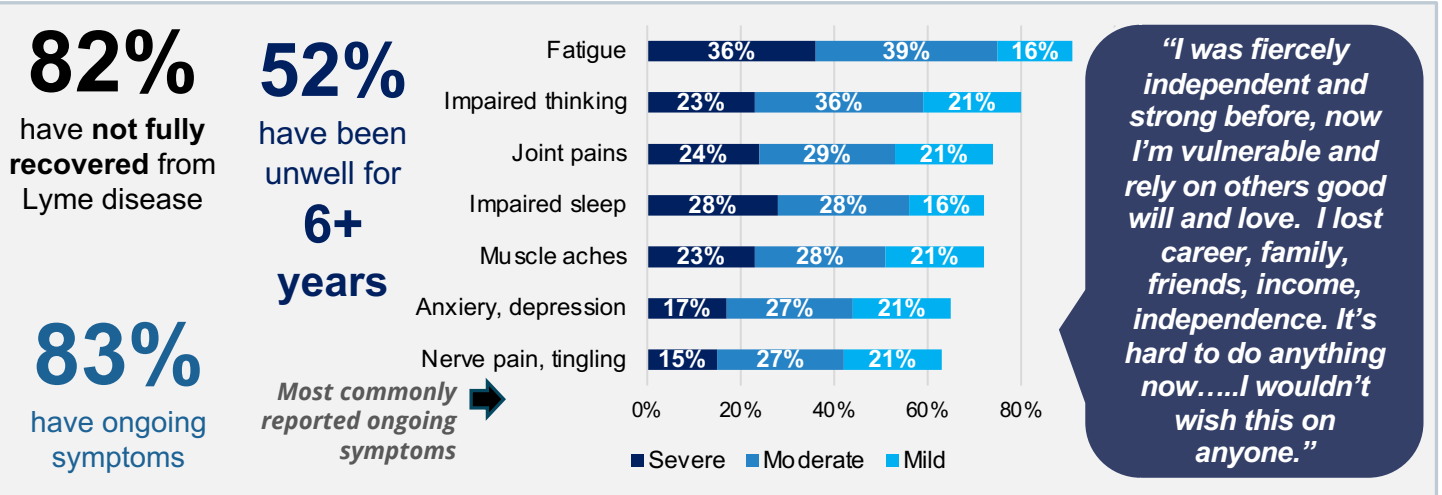
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ONGOING NEEDS

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SURVEY SUGGESTS SIGNIFICANT ONGOING NEEDS FOR MANY WITH LYME DISEASE



<i>Has Lyme disease affected you in other ways?</i>	
Affected social life and hobbies	79%
Financial loss	65%
Affected relationships with family and friends	61%
Career consequences	55%
Stigma associated with Lyme disease, chronic illness	48%
Loss of independence	47%
Educational consequences	25%

What could have been better?

“Lyme has changed my life.. literally my life was before & after.. I’ve watched my youth pass me by from bed for 2 decades.. but the hardest of all was people not believing me.”

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 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 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 between 1st February 2024 and 30th April 2024, **475 reported a diagnosis of Lyme disease confirmed by a qualified health professional 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/>