



Lyme Disease Experience Survey



L R C
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.*

AWARENESS

- 111** responses from **residents of Scotland;** all diagnosed with Lyme disease by a qualified healthcare professional
- 86%** were bitten in Scotland of which **>80%** bitten in Highlands & Islands
- 60%** were bitten in local fields, woodlands farmlands **20%** bitten in the garden
- 33%** were not aware of need to protect against tick bites prior to illness
- 42%** were not aware of Lyme disease prior to illness

Scotland must prioritise raising awareness of tick bites and Lyme disease

DIAGNOSIS

In a letter of June 2019, Scotland's CMO directs practitioners to NICE guideline 95 on management of Lyme disease, which *"aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment"*.

64% respondents had an Erythema Migrans (EM) rash

Time from symptoms to Lyme disease diagnosis

From onset of symptoms

- 71%** not diagnosed within 4 weeks
- 36%** not diagnosed for > 1 year
- 15%** not diagnosed for > 5 years

Timely diagnosis of Lyme disease in Scotland must improve

TREATMENT

NICE guideline 95 states that *'Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery'*.

- 68%** had difficulty accessing treatment
- 93%** had antibiotics
- 57%** delay of > one month
- 44%** delay of > 3 months
- 19%** experienced delay of 2 years or more
- 78%** did not fully recover after first antibiotic
- Of 68% who had difficult accessing treatment, **86%** say lack of disease awareness & expertise amongst health professionals was **top barrier** to treatment

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

ONGOING NEEDS

NICE guideline 95 also states that *'Symptoms can be more severe and long-lasting if treatment is delayed'*

- 72%** have ongoing symptoms
- 55%** have been unwell for > 2 years
- 32%** have been unwell for > 6 years
- Most commonly reported ongoing symptoms**

"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."

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

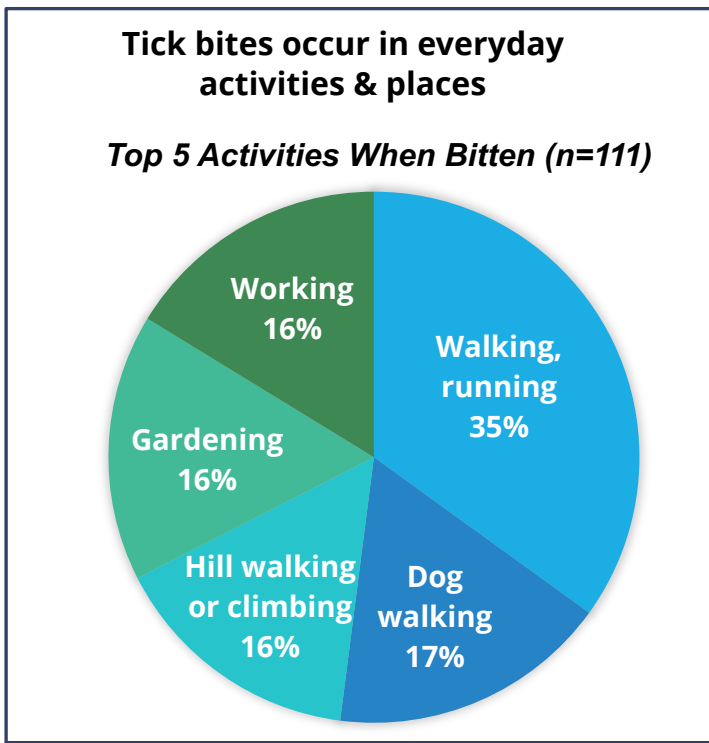
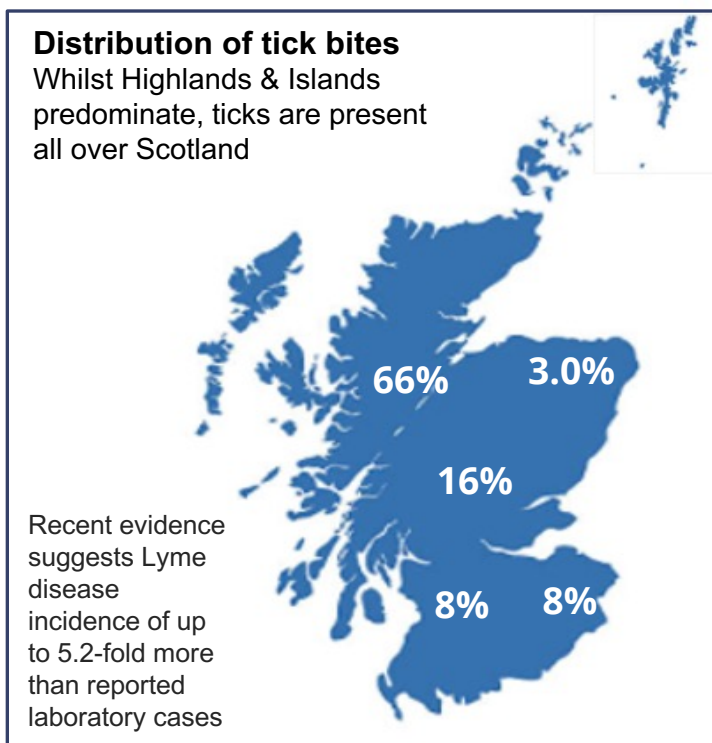


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AWARENESS

Scotland must prioritise raising awareness of tick bites and Lyme disease

<p>111 responses from residents of Scotland; all diagnosed with Lyme disease by a qualified healthcare professional</p>	<p>86% were bitten in Scotland of which >80% bitten in Highlands & Islands</p>	<p>60% were bitten in local fields, woodlands farmlands 20% bitten in the garden</p>	<p>33% were not aware of need to protect against tick bites prior to illness</p>	<p>42% were not aware of Lyme disease prior to illness</p>
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Location when tick bite occurred (n=111)	
Local fields, woodlands	29%
Farmland, countryside	31%
In the garden	20%
Mountains, valleys, forests, wilds	41%
Indoors (via a pet)	2%

30% didn't recall a tick bite

Of those who found & removed a tick, only **40%** used a recognised tick removal tool

In a letter of June 2019, Scotland's CMO states - *"Frontline healthcare practitioners have a key role not only in the early diagnosis and management of Lyme disease cases, but also in promoting awareness of ticks and tick borne infections amongst their patients. NHS Boards should promote awareness raising by frontline Healthcare Professionals, including those in Primary Care and GP practices."*



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TREATMENT

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

NICE guideline 95 states that *'Prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery'*.

Survey evidence highlights missed opportunities for effective treatment.

<p>68% had difficulty accessing treatment</p> <p>93% had antibiotics</p>	<p>Time from symptoms to first antibiotic</p> <p>57% delay of > one month</p> <p>44% delay of > 3 months</p>	<p>19% experienced delay of 2 years or more</p>	<p>78% did not fully recover after first antibiotic</p>	<p>Of 68% who had difficulty accessing treatment,</p> <p>86% say lack of disease awareness & expertise amongst health professionals was top barrier to treatment</p>
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Time from onset of Lyme disease symptoms to first antibiotic

Time from onset	Percentage
Within 48 hours	11%
Within 1 week	12%
1 to 2 weeks	7%
2 to 3 weeks	8%
3 to 4 weeks	6%
1 to 3 months	14%
4 to 6 months	12%
7 to 12 months	6%
1 to 2 years	7%
> 2 years	19%

"Had to fight - got treatment from GP despite having the tick, rash was not bulls eye so not accepted as EM despite having symptoms.

When still had symptoms following doxycycline was refused further treatment-- sent tick for testing it was positive. GP contacted ID who stated no further treatment.

MSP contacted and intervened on my behalf resulting in full course of amoxicillin in line with NICE guidelines which did resolve symptoms."

Just **25%** have recovered from Lyme disease

Have you now recovered from Lyme disease? (n=111)

Recovery Status	Percentage
No	24%
Yes	25%
Partial recovery	40%
Not sure	11%

Of 68% who had difficulty accessing treatment	
Key Reasons for Difficulty Accessing Treatment	
Lack of disease awareness / expertise of health professionals	86%
Misdiagnosis resulting in delayed diagnosis and treatment	60%
Diagnosis excluded due to negative / inconclusive blood test*	54%
Restrictive treatment guidelines (*despite Lyme symptoms)	49%
Cost of private treatment	44%
Distance to travel for treatment	31%
Stigma associated with Lyme disease	27%

68%

have been unwell with Lyme disease for a year or more

32%

have been unwell for > 6 years

72%

have ongoing symptoms



Lyme Disease Experience Survey



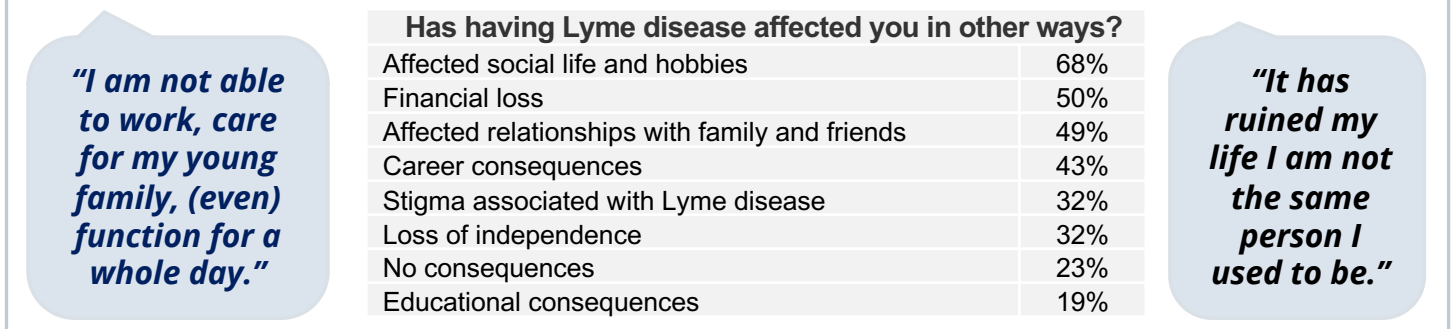
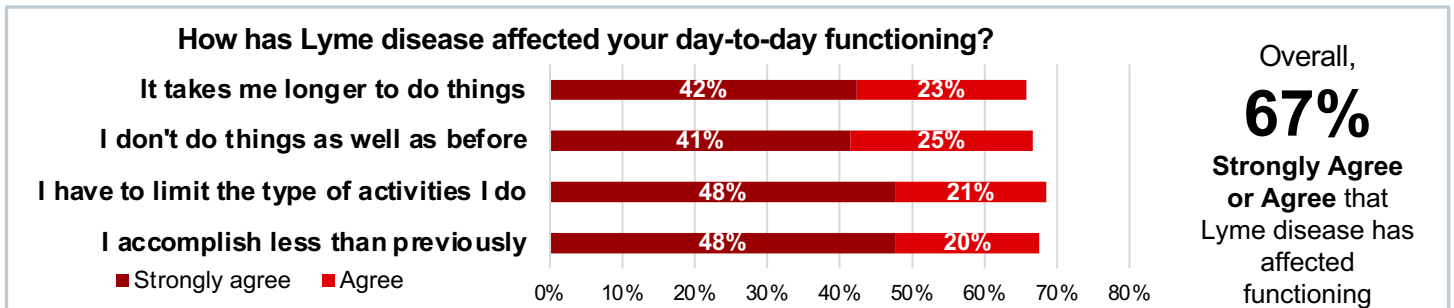
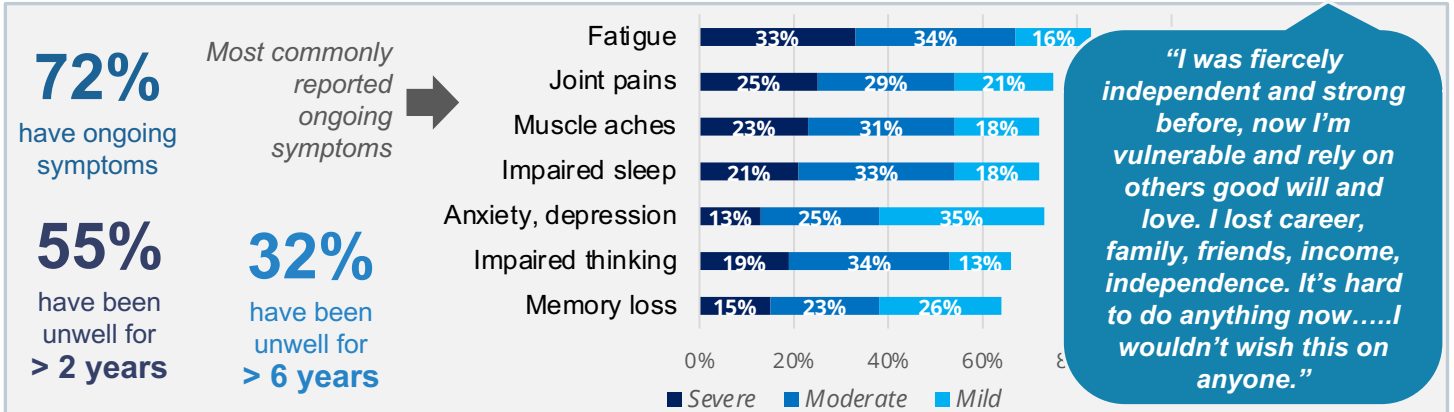
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ONGOING NEEDS

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

NICE guideline 95 states that *'Symptoms can be more severe and long-lasting if treatment is delayed'*. **Survey evidence suggest significant ongoing needs for many with Lyme disease.**



"It's hard to condense how much this has impacted me. I can no longer make plans that cannot be cancelled at short notice, I can't travel abroad.....I have retained a handful of friends who understand what it is like to not have day to day control of my health. I can no longer undertake tasks such as shopping and have a husband who now acts as my carer."

What could have been better?
"More awareness of Lyme disease in Scotland and knowledge on how it should be treated and the fact that sometimes treatment doesn't work. Communication between GP and other specialists to be made aware of Lyme diagnosis."

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 aimed 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.

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 30th April 2024, **475 reported a diagnosis of Lyme disease confirmed by a qualified health professional; 111 of these responses were from Ireland and formed 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

- Scottish Government, Chief Medical Officer Letter re: *Identification and Management of Lyme Disease – Educational Resources*, July 2019 <https://www.publications.scot.nhs.uk/files/cmo-2019-07.pdf>
- NICE Guideline [NG95] Lyme Disease <https://www.nice.org.uk/guidance/ng95>
- Incidence and management of Lyme disease: a Scottish general practice retrospective study, Mavin et al, BJGP Open, April 2024 <https://pubmed.ncbi.nlm.nih.gov/38670577/>