LRC Lyme Disease Experience Survey

Frequently Asked Questions (FAQs)

SURVEY RELATED QUESTIONS

1) WHAT IS THE PURPOSE OF THE LRC SURVEY?

Lyme disease has been around for many decades, yet limited information makes it difficult to drive improvements in diagnosis, treatment and care. The goal of the survey is to create knowledge that can be used to benefit patients with Lyme disease. Although many make a full recovery, others remain ill after antibiotic treatment. (1) This survey aims to record patients' experiences of diagnosis, treatments and outcomes, to support development of patient-centred Lyme disease data.

2) WHO HAS DEVELOPED THE SURVEY?

The survey has been developed by, and will be analysed by, a small team of medical advisors (co-authors of the Royal College of General Practitioners (RCGP) Lyme Disease Toolkit) and Trustees of the Lyme Resource Centre. (2)
The survey is the copyright of LRC and the survey authors.

3) WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS SURVEY?

The NICE Guideline on Lyme disease has identified "*the lack of epidemiological data on the incidence, clinical features, management and outcome of Lyme disease in the UK*". Similar issues exist in the Republic of Ireland and elsewhere in the world. (3)

Your participation in this survey will help to form a body of evidence to address these issues, encourage research and support healthcare professionals to improve diagnosis and treatment of Lyme disease.

4) WHO CAN PARTICIPATE?

Any adults or children in the UK and the Republic of Ireland who have been diagnosed with Lyme disease by a qualified healthcare professional. If under the age of 18 years then we request that a parent or guardian completes the questionnaire on their behalf. We are gathering information on treatment responses amongst people who have been diagnosed with Lyme disease, past and present. We would value survey responses from those who remain unwell after treatment and also from those who have fully recovered

5) DO I HAVE TO LIVE IN THE UK OR REPUBLIC OF IRELAND TO PARTICIPATE?

Yes, the survey is primarily for residents of the UK or the Republic of Ireland regardless of where infection occurred. However if you live overseas but strongly suspect that you contracted Lyme disease in the UK or Republic of Ireland then you are also welcome to complete the survey.

6) HOW DO I PARTICIPATE IN THE SURVEY?

Just click on the following link - no sign in details are required. (ADD SURVEY LINK)
Please note that the survey should ideally be completed in one session.
The survey should take 20-30 minutes to complete, though some cases may take longer. Note, if available, it may help to have relevant medical information e.g. dates, medication details (medicine, dosage, duration) etc. close at hand when answering questions, though this may not be essential.

7) WHY DO I NEED TO HAVE MY TREATMENT DETAILS TO HAND BEFORE STARTING THE SURVEY?

The survey will ask you questions about how and when you were diagnosed with Lyme disease, and if treated, what treatment you were given/prescribed, the symptoms you have experienced and any ongoing health issues and related consequences. Having the information to hand will make it easier for you to complete the survey accurately, and for us to interpret responses correctly.

8) CAN SOMEONE ELSE COMPLETE THE SURVEY ON MY BEHALF?

Yes, with your agreement, a family member, friend, carer or guardian can complete the survey on your behalf. **We request that there is only one response per individual case.**

9) IS THE SURVEY ONLY ACCESSIBLE ONLINE?

Yes, the survey can only be completed online via either a computer, tablet or phone. Note, it may be easiest to complete on a computer or tablet.

10) WHY IS IT RECOMMENDED TO COMPLETE THE SURVEY IN ONE SITTING?

We recommend choosing a time and environment where you are comfortable, have relevant information to hand, and are able to complete the survey fully.

To maintain anonymity and due to survey tool design, survey responses are only recorded once the full survey is submitted (click DONE) at the end. Information entered is saved when you navigate forwards (click NEXT) through the survey pages; note that you can navigate backwards and forwards within the survey pages as you complete it. However, if you partially complete the survey, leave it for some time, then return later, the original partially completed survey may not be saved, risking the need to start again. If, for whatever reason, you feel unable to complete the survey, you have the opportunity to restart the survey afresh at a time that suits you.

11) WILL MY DATA BE CONFIDENTIAL?

Yes. Participation in the survey is entirely voluntary, and anonymous. There is no requirement to share any identifying details. Your data will be managed in line with LRC's data privacy policy. https://www.lymeresourcecentre.com/privacy-policy

12) HOW WILL MY SURVEY DATA BE USED?

The information you provide will be combined with other survey responses to highlight the reality of Lyme disease experiences in the UK and Republic of Ireland. Bringing together data from many people may identify patterns in illness, treatment or recovery. All references to 'data' below, refer to aggregated, anonymous survey data.

We hope to form a body of evidence to encourage research, and support improvement in diagnosis and treatment of Lyme disease.

The data will be analysed by the LRC survey team and possibly with selected trusted partners.

We aim to use the survey data to analyse, explore and formally record patterns of disease and consequences of illness. The findings and insights will be published in multiple and different formats including, but not limited to, written articles, academic papers, formal presentations, educational webinars and may be shared on social media.

A summary of insights from the survey data will be published on the LRC website, so you can see the findings in an easy to access form.

We will share survey analysis and outcomes with (but not restricted to) healthcare professionals, other Lyme charities, policy makers and other relevant professional organisations with whom LRC works. Such content will also be made available in the public domain, via our website and social media posts.

Information provided in the survey will be managed in line with the Lyme Resource Centre's data privacy policy. https://www.lymeresourcecentre.com/privacy-policy

13) HOW DO I KNOW WHAT HAPPENS WITH SURVEY INSIGHTS?

A summary of insights from the survey data will be published on the LRC website, so you can see the findings in an easy to access form.

You can also provide your email address to the Lyme Resource Centre via this link: https://www.surveymonkey.com/r/5JHDWZP.
This will allow us to email you any summaries of the survey findings, future surveys, news on work of LRC and other communications. Your email address will be managed in line with LRC's data privacy policy.
https://www.lymeresourcecentre.com/privacy-policy

14) WILL THERE BE FURTHER SURVEYS?

Yes possibly - we may develop further surveys in the future based on the outcomes and findings of this survey or to explore some topics in more detail.

LYME DISEASE RELATED QUESTIONS / GUIDANCE

WHAT IS AN ERYTHEMA MIGRANS(EM) RASH AND WHAT DOES IT LOOK LIKE?

Erythema Migrans (EM) rash is the rash that occurs only in Lyme disease - about two thirds of people infected may have the rash. Presence of the EM rash means treatment with antibiotics is needed.

The rash has various appearances. The much reported 'bull's eye' rash has multiple rings, but is seen less commonly. More often, it is a uniform red/pink/ blue-ish/purple-ish expanding rash. It can appear on the site of the tick bite, or in other parts of the body in later disease (distant to the original bite) and may be multiple in number. Sometimes, it may be fleetingly present when the skin is warm (e.g. following a hot shower), fading away as the skin cools.

Of note, the rash can look very different in those with deeper skin tones, where they may be a red/pink/purple tinge to the skin, or a darkening of the skin tone. We have tried our best to provide links that include examples in more melanated skin, however, unfortunately there is a scarcity of examples of erythema migrans in the full range of skin tones online and in educational materials.

Some examples are shown in the following links:
https://www.nice.org.uk/guidance/ng95/resources/lyme-disease-rash-images-pdf-4792273597
https://health.maryland.gov/phpa/oideor/czvbd/shared%20documents/lyme_md_poster_final.pdf
https://www.pcds.org.uk/clinical-guidance/lyme-disease
https://www.bayarealyme.org/get-help/skin-rashes/
https://www.cdc.gov/lyme/resources/NCEZID_rash_poster3r1-508.pdf
https://www.aad.org/public/diseases/a-z/lyme-disease-signs
https://dermnetnz.org/topics/erythema-migrans-images

Example of the erythema migrans rash in more melanated skin tones:
https://phil.cdc.gov/Details.aspx?pid=14482

WHAT DOES BORRELIAL LYMPHOCYTOMA LOOK LIKE?

This is a lump/swelling that can appear on ears, nipples or genitals. It would be diagnosed by your doctor (scroll down for the ear lobe).
https://www.aad.org/public/diseases/a-z/lyme-disease-signs

References

(1) Chronic Symptoms Following Infections | What We Do | NCEZID | CDC

(2) Lyme disease toolkit: Introduction - Ticks and Lyme disease | RCGP Learning

(3) Recommendations for research | Lyme disease | Guidance | NICE