NICE National Institute for
Health and Care Excellence

Lyme disease

Quality standard
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This standard is based on NG95.

This standard should be read in conjunction with QS121.

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Quality statement 1: Erythema migrans

Quality statement

People presenting with erythema migrans are diagnosed and treated for Lyme disease based on clinical assessment, without laboratory testing.

Rationale

Erythema migrans is a skin rash that is associated specifically with Lyme disease. It can be identified by clinical assessment and so serological tests are not needed for diagnosis, as shown in NICE's visual summary of the recommendations for testing for Lyme disease. In some cases, serological tests may be misleading because they may be negative when the rash occurs. Prompt diagnosis and treatment of Lyme disease based on the presence of erythema migrans will help to reduce the risk of further symptoms developing.

Quality measures

Structure

Evidence that healthcare professionals are trained to recognise symptoms of Lyme disease.

Data source: Local data collection, for example, audits of annual performance reviews and records of continuing professional development, such as completion of the Royal College of General Practitioners (RCGP) e-learning course, participating in events or using resources for education, training and quality improvement (such the RCGP Lyme disease toolkit: resources for education, training and quality improvement).

Process

Proportion of people diagnosed with Lyme disease based on erythema migrans without laboratory testing.

Numerator – the number in the denominator who did not have laboratory testing.

Denominator – the number of people diagnosed with Lyme disease who had erythema migrans.

Data source: Local data source, for example, an audit of patient records.

What the quality statement means for different audiences

Service providers (such as general practice, community pharmacies, out-of-hours services and emergency departments) have systems in place to ensure that people presenting with erythema migrans are diagnosed and treated for Lyme disease, without having laboratory tests. They also ensure that GPs and other healthcare professionals are trained to recognise symptoms of Lyme disease, for example, through completion of the RCGP e-learning course, participating in events or using resources for education, training and quality improvement (such the RCGP Lyme disease toolkit: resources for education, training and quality improvement).

Healthcare professionals (such as GPs, practice nurses, pharmacists, and doctors in out-of-hours services and emergency departments) diagnose and treat people presenting with erythema migrans for Lyme disease, without ordering laboratory tests. They are trained to recognise symptoms of Lyme disease, which include erythema migrans, for example, through completion of the RCGP e-learning course, participating in events or using resources for education, training and quality improvement (such the RCGP Lyme disease toolkit: resources for education, training and quality improvement).

Commissioners (clinical commissioning groups and NHS England) ensure that they commission services in which people presenting with erythema migrans are diagnosed and treated for Lyme disease based on clinical assessment, without laboratory tests.

People who go to their healthcare professional with a spreading red rash that is identified as 'erythema migrans' are diagnosed with Lyme disease from the rash alone and do not need to have blood tests. They are treated for Lyme disease based on this diagnosis.

Source guidance

Lyme disease. NICE guideline NG95 (2018), recommendation 1.2.11

Definition of terms used in this quality statement

Erythema migrans

Erythema migrans is a red rash, specific to Lyme disease, that increases in size and may sometimes have a central clearing. It is not usually itchy, hot or painful. It usually becomes visible from 1 to 4 weeks after a tick bite (but can appear from 3 days to 3 months) and lasts for several weeks. It is usually at the site of a tick bite, and appears in around two-thirds of cases. See also NICE's resource on different presentations of erythema migrans. [NICE's guideline on Lyme disease, recommendation 1.2.1]

Equality and diversity considerations

Healthcare professionals should be aware that it may be more difficult to identify erythema migrans in people with darker skin tones; this may be of particular relevance to people in black, Asian and minority ethnic groups.

Quality statement 2: Repeat ELISA tests

Quality statement

People with suspected Lyme disease without erythema migrans who have a negative enzyme-linked immunosorbent assay (ELISA) test carried out within 4 weeks of their symptoms starting have the test repeated 4 to 6 weeks later if Lyme disease is still suspected.

Rationale

The timing of the initial ELISA test is important for diagnosing Lyme disease in people without erythema migrans. If the test is performed too early (within 4 weeks of symptom onset) the person may not have developed antibodies to the bacteria that causes Lyme disease, resulting in a 'false negative' result. People in whom Lyme disease is still suspected and who had a negative initial ELISA test result may have had the test too early. Repeating the test 4 to 6 weeks after the first test supports an accurate diagnosis. The diagnostic process is summarised in NICE's visual summary of the recommendations for testing for Lyme disease.

Quality measures

Structure

Evidence of local arrangements to provide repeat ELISA tests 4 to 6 weeks after an initial negative ELISA test result for people without erythema migrans in whom Lyme disease is still suspected.

Data source: Local data collection, for example, service specifications and written clinical protocols.

Process

Proportion of people without erythema migrans who had a negative initial ELISA test within

4 weeks of symptoms starting, and in whom Lyme disease is still suspected, who have a repeat ELISA test 4 to 6 weeks after the first test.

Numerator – the number in the denominator who have a repeat ELISA test 4 to 6 weeks after the first test.

Denominator – the number of people without erythema migrans who had a negative initial ELISA test within 4 weeks of symptoms starting, and in whom Lyme disease is still suspected.

Data source: Local data collection, for example, an audit of patient records.

What the quality statement means for different audiences

Service providers (such as primary care and local microbiology laboratories) have local arrangements in place to ensure that people without erythema migrans in whom Lyme disease is still suspected after an initial negative ELISA test result for Lyme disease within 4 weeks of onset of symptoms have the test repeated 4 to 6 weeks later. If there is no local diagnostic service, the sample is tested at the Rare and Imported Pathogens Laboratory (RIPL).

Healthcare professionals (such as GPs and clinicians in secondary care) repeat an ELISA test 4 to 6 weeks after the first test for people without erythema migrans in whom Lyme disease is still suspected after an initial negative ELISA test result for Lyme disease within 4 weeks of onset of symptoms. They are aware of local arrangements to support ordering the repeat test.

Commissioners (such as clinical commissioning groups and NHS England) commission local microbiology laboratory services to perform a repeat ELISA test 4 to 6 weeks after the first test for people without erythema migrans if Lyme disease is still suspected after an initial negative ELISA test result for Lyme disease within 4 weeks of onset of symptoms. If there is no local diagnostic service, the sample is tested at the RIPL.

People without erythema migrans who had a negative blood test for Lyme disease in the 4 weeks after their symptoms began, but continue to have symptoms, have another blood test 4 to 6 weeks after their first test. This will help to make sure they are correctly diagnosed.

Source guidance

Lyme disease. NICE guideline NG95 (2018), recommendation 1.2.17

Definition of terms used in this quality statement

ELISA test

An ELISA test for Lyme disease, which detects antibodies produced in response to infection by the bacteria that causes Lyme disease (different species of *Borrelia*). The diagnostic process is summarised in NICE's visual summary of the recommendations for testing for Lyme disease. [NICE's guideline on Lyme disease, recommendation 1.2.17, terms used in this guideline and evidence reviews for diagnostic tests, and expert opinion].

Quality statement 3: Antibiotic treatment

Quality statement

People with Lyme disease have initial antibiotic treatment, with the antibiotic, dosage and duration determined by their symptoms.

Rationale

Prompt treatment of Lyme disease with an initial antibiotic at adequate dosage and duration, chosen according to the person's symptoms (for example, presentation with erythema migrans or fever) and in line with the recommendations on antibiotic treatment in the NICE guideline on Lyme disease, will stop or reduce the symptoms of Lyme disease and may also prevent the relapse of symptoms.

Quality measures

Structure

Evidence that local formularies align with NICE's recommendations on antibiotic treatment for Lyme disease, so that healthcare professionals in primary and secondary care prescribe an antibiotic to people with Lyme disease according to their symptoms.

Data source: Local data collection, for example, local formularies.

Process

a) Proportion of people diagnosed with Lyme disease who are given the initial antibiotic recommended by NICE for their symptoms.

Numerator – the number in the denominator who are given the antibiotic recommended by NICE for their symptoms.

Denominator – the number of people diagnosed with Lyme disease.

Data source: Local data collection, for example, a case note review of patient records.

b) Proportion of people diagnosed with Lyme disease who are given the initial antibiotic recommended by NICE for their symptoms at the recommended dosage.

Numerator – the number in the denominator who are given the antibiotic recommended by NICE for their symptoms at the recommended dosage.

Denominator – the number of people diagnosed with Lyme disease.

Data source: Local data collection, for example, a case note review of patient records.

c) Proportion of people diagnosed with Lyme disease who are given the initial antibiotic recommended by NICE for their symptoms for the recommended duration.

Numerator – the number in the denominator who are given the antibiotic recommended by NICE for their symptoms for the recommended duration.

Denominator – the number of people diagnosed with Lyme disease.

Data source: Local data collection, for example, a case note review of patient records.

What the quality statement means for different audiences

Service providers (primary care and NHS hospital trusts) ensure that they develop or have access to a local antibiotic formulary that is aligned with NICE's recommendations, according to the symptoms of Lyme disease.

Healthcare professionals (such as GPs, prescribers in A&E departments, and specialists in secondary and tertiary care) treat Lyme disease with antibiotics. They follow local antibiotic formularies to ensure that they prescribe the antibiotic, dosage and duration that is aligned with NICE's recommendations, as determined by the person's symptoms.

Commissioners (such as NHS England and clinical commissioning groups) ensure that service specifications require antibiotic treatment that is aligned with NICE's recommendations to be prescribed to people with Lyme disease according to their symptoms.

People diagnosed with Lyme disease have antibiotic treatment that is chosen according to their symptoms. This is to make sure that they are given the antibiotics recommended by NICE, at the right dose and for long enough to treat their symptoms.

Source guidance

Lyme disease. NICE guideline NG95 (2018), recommendations 1.3.4 and 1.3.5

Definition of terms used in this quality statement

Antibiotic treatment determined by their symptoms

Recommended antibiotics, dosages and duration of initial treatment of Lyme disease, according to the person's symptoms, are given in tables 1 and 2 of NICE's guideline on Lyme disease. [NICE's guideline on Lyme disease, recommendations 1.3.4 and 1.3.5]

Quality statement 4: Awareness of Lyme disease

Quality statement

Local authorities organise health promotion activities with organisations in their area to raise public awareness about how to prevent Lyme disease.

Rationale

Increasing public knowledge of Lyme disease and how to reduce the risk of infection will help to prevent Lyme disease. This includes raising awareness of tick habitats, which is important because infected ticks can be found throughout the UK, including urban parks. Information to support prevention should also include recommended methods of tick removal, checking the skin for ticks, wearing clothes that do not expose the skin and using tick repellents. Engagement with a range of local organisations (including NHS organisations) will encourage prevention, raise the profile of Lyme disease and address local needs.

Quality measures

Structure

a) Evidence that local authorities have organised activities to promote awareness of how to prevent Lyme disease.

Data source: Local data collection, for example, records of implementation plans, which could include using material from Public Health England's toolkit and resources for local authorities.

b) Evidence that local authorities have worked with organisations in their area to promote awareness of how to prevent Lyme disease.

Data source: Local data collection, for example, records of agreements with organisations, which could include agreeing to display material from Public Health England's toolkit and resources for local authorities.

Outcome

Levels of public awareness of how to prevent Lyme disease after locally driven health promotion activities.

Data source: Local data collection, for example, results from surveys and questionnaires.

What the quality statement means for different audiences

Public health practitioners ensure that they implement local authority awareness-raising activities about the potential risks of tick bites and Lyme disease, and how to reduce the risk. Activities could include providing up-to-date leaflets, posters for display in local GP practices, online information (including social media) and organising outreach events tailored to local needs. Activities are timed to coincide with periods associated with a higher risk of tick exposure, and with other relevant local public health events. Existing resources are available from Public Health England's toolkit and resources for local authorities and the Royal College of General Practitioners (RCGP) Lyme disease toolkit.

Commissioners (local authorities) ensure that they provide up-to-date, consistent and coordinated information about Lyme disease, such as Public Health England's toolkit and resources for local authorities and the RCGP Lyme disease toolkit, to raise awareness of the potential risks of tick bites and tick-borne disease, and how to reduce the risk. They work with organisations, such as local NHS organisations, organisations involved in leisure and recreation, and community groups to raise awareness of Lyme disease.

People in the community can find out about Lyme disease and how to prevent it through events and information provided by local organisations.

Source guidance

Lyme disease. NICE guideline NG95 (2018), recommendation 1.1.3

Equality and diversity considerations

Information should be in a format that suits people's needs and preferences. It should accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in NHS England's Accessible Information Standard.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See our webpage on quality standard advisory committees for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- quality of life of people with Lyme disease
- public awareness of Lyme disease
- awareness of Lyme disease in people from occupational groups at increased risk
- patient experience of people with Lyme disease in primary care.

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- NHS outcomes framework
- Public health outcomes framework for England
- Quality framework for public health.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact statement for the NICE guideline on Lyme disease to help estimate local costs.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments for this quality standard are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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Endorsing organisations

This quality standard has been endorsed by the following organisations, as required by the Health and Social Care Act (2012):

- NHS England
- Department of Health and Social Care

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Royal College of General Practitioners (RCGP)
- Royal College of Physicians (RCP)
- Lyme Disease Action
- Primary Care Rheumatology and Musculoskeletal Medicine Society
- Royal College of Paediatrics and Child Health
- Association of British Neurologists (ABN)
- Caudwell LymeCo Charity
- Lyme Disease UK
- British Infection Association
- Royal College of Pathologists