

# Lyme disease

NICE guideline

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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## Overview

This guideline covers diagnosing and managing Lyme disease. It aims to raise awareness of when Lyme disease should be suspected and ensure that people have prompt and consistent diagnosis and treatment. It does not cover preventing Lyme disease.

### *Who is it for?*

- Healthcare professionals including GPs, nurses, specialists and microbiologists
- Commissioners and providers
- People with Lyme disease, their families and carers

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

### 1.1 *Awareness of Lyme disease*

#### 1.1.1 Be aware that:

- the bacteria that cause Lyme disease are transmitted by the bite of an infected tick
- ticks are mainly found in grassy and wooded areas, including urban gardens and parks
- tick bites may not always be noticed
- infected ticks are found throughout the UK and Ireland, and although some areas appear to have a higher prevalence of infected ticks, prevalence data are incomplete
- particularly high-risk areas are the South of England and Scottish Highlands but infection can occur in many areas
- Lyme disease may be more prevalent in parts of central, eastern and northern Europe (including Scandinavia) and parts of Asia, the US and Canada.

#### 1.1.2 Be aware that most tick bites do not transmit Lyme disease and that prompt, correct removal of the tick reduces the risk of transmission.

#### 1.1.3 Give people advice about:

- where ticks are commonly found (such as grassy and wooded areas, including urban gardens and parks)
- the importance of prompt, correct tick removal and how to do this (see the Public Health England website for [information on removing ticks](#))
- covering exposed skin and using insect repellents that protect against ticks

- how to check themselves and their children for ticks on the skin
- sources of information on Lyme disease, such as [Public Health England](#), and organisations providing information and support, such as patient charities.

To find out why the committee made the recommendations on awareness of Lyme disease and how they might affect practice, see [rationale and impact](#).

## 1.2 *Diagnosis*

### Clinical assessment

#### 1.2.1 Diagnose Lyme disease in people with erythema migrans, a red rash that:

- increases in size and may sometimes have a central clearing
- is not usually itchy, hot or painful
- usually becomes visible from 1 to 4 weeks (but can appear from 3 days to 3 months) after a tick bite and lasts for several weeks
- is usually at the site of a tick bite.

NICE has also produced a [resource](#) with images showing erythema migrans.

#### 1.2.2 Be aware that a rash, which is not erythema migrans, can develop as a reaction to a tick bite that:

- usually develops and recedes during 48 hours from the time of the tick bite
- is more likely than erythema migrans to be hot, itchy or painful
- may be caused by an inflammatory reaction or infection with a common skin pathogen.

#### 1.2.3 Consider the possibility of Lyme disease in people presenting with several of the following symptoms, because Lyme disease is a possible but uncommon cause of:

- fever and sweats
- swollen glands

- malaise
- fatigue
- neck pain or stiffness
- migratory joint or muscle aches and pain
- cognitive impairment, such as memory problems and difficulty concentrating (sometimes described as 'brain fog')
- headache
- paraesthesia.

1.2.4 Consider the possibility of Lyme disease in people presenting with symptoms and signs relating to 1 or more organ systems (focal symptoms) because Lyme disease is a possible but uncommon cause of:

- neurological symptoms, such as facial palsy or other unexplained cranial nerve palsies, meningitis, mononeuritis multiplex or other unexplained radiculopathy; or rarely encephalitis, neuropsychiatric presentations or unexplained white matter changes on brain imaging
- inflammatory arthritis affecting 1 or more joints that may be fluctuating and migratory
- cardiac problems, such as heart block or pericarditis
- eye symptoms, such as uveitis or keratitis
- skin rashes such as acrodermatitis chronica atrophicans or lymphocytoma.

1.2.5 If a person presents with symptoms that suggest the possibility of Lyme disease, explore how long the person has had symptoms and their history of possible tick exposure, for example, ask about:

- activities that might have exposed them to ticks
- travel to areas where Lyme disease is known to be highly prevalent.

1.2.6 Do not rule out the possibility of Lyme disease in people with symptoms but no clear history of tick exposure.



- 1.2.7 Do not diagnose Lyme disease in people without symptoms, even if they have had a tick bite.
- 1.2.8 Be cautious about diagnosing Lyme disease in people without a supportive history or positive serological testing because of the risk of:
- missing an alternative diagnosis
  - providing inappropriate treatment.
- 1.2.9 Follow usual clinical practice to manage symptoms, for example, pain relief for headaches or muscle pain, in people being assessed for Lyme disease.
- 1.2.10 Take into account that people with Lyme disease may have symptoms of cognitive impairment and may have difficulty explaining their symptoms. For adults, follow the recommendations in NICE's guideline on [patient experience in adult NHS services](#).

To find out why the committee made the recommendations on clinical assessment and how they might affect practice, see [rationale and impact](#).

## Laboratory investigations to support diagnosis

NICE has also produced a [visual summary](#) of the recommendations on testing for Lyme disease.

- 1.2.11 Diagnose and treat Lyme disease without laboratory testing in people with erythema migrans.
- 1.2.12 Use a combination of clinical presentation and laboratory testing to guide diagnosis and treatment in people without erythema migrans. Do not rule out diagnosis if tests are negative but there is high clinical suspicion of Lyme disease.
- 1.2.13 If there is a clinical suspicion of Lyme disease in people without erythema migrans:
- offer an enzyme-linked immunosorbent assay (ELISA) [test](#) for Lyme disease and
  - consider starting treatment with antibiotics while waiting for the results if there is a high clinical suspicion.

- 1.2.14 Test for both IgM and IgG antibodies using ELISAs based on purified or recombinant antigens derived from the VlsE protein or its IR6 domain peptide (such as C6 ELISA).
- 1.2.15 If the ELISA is positive or equivocal:
- perform an immunoblot test for Lyme disease **and**
  - consider starting treatment with antibiotics while waiting for the results if there is a high clinical suspicion of Lyme disease.
- 1.2.16 If the ELISA for Lyme disease is negative and the person still has symptoms, review their history and symptoms, and think about the possibility of an alternative diagnosis.
- 1.2.17 If Lyme disease is still suspected in people with a negative ELISA who were tested within 4 weeks from symptom onset, repeat the ELISA 4 to 6 weeks after the first ELISA test.
- 1.2.18 If Lyme disease is still suspected in people with a negative ELISA who have had symptoms for 12 weeks or more, perform an immunoblot test.
- 1.2.19 Diagnose Lyme disease in people with symptoms of Lyme disease and a positive immunoblot test.
- 1.2.20 If the immunoblot test for Lyme disease is negative (regardless of the ELISA result) but symptoms persist, consider a discussion with or referral to a specialist, to:
- review whether further tests may be needed for suspected Lyme disease, for example, synovial fluid aspirate or biopsy, or lumbar puncture for cerebrospinal fluid analysis **or**
  - consider alternative diagnoses (both infectious, including other tick-borne diseases, and non-infectious diseases).
- Choose a specialist appropriate for the person's history or symptoms, for example, an adult or paediatric infection specialist, rheumatologist or neurologist.
- 1.2.21 If the immunoblot test for Lyme disease is negative and symptoms have resolved, explain to the person that no treatment is required.

**1.2.22 Carry out tests for Lyme disease only at laboratories that:**

- are accredited by the UK accreditation service (UKAS) and
- use validated tests (validation should include published evidence on the test methodology, its relation to Lyme disease and independent reports of performance) and
- participate in a formal external quality assurance programme.

**1.2.23 Do not routinely diagnose Lyme disease based only on tests done outside the NHS, unless the laboratory used is accredited, participates in formal external quality assurance programmes and uses validated tests (see recommendation 1.2.22). If there is any doubt about tests:**

- review the person's clinical presentation and
- carry out testing again using a UKAS-accredited laboratory and/or seek advice from a national reference laboratory.

To find out why the committee made the recommendations on laboratory investigations and how they might affect practice, see [rationale and impact](#).

## **Information for people being tested for Lyme disease**

**1.2.24 Tell people that tests for Lyme disease have limitations. Explain that both false-positive and false-negative results can occur and what this means.**

**1.2.25 Explain to people that most tests for Lyme disease assess for the presence of antibodies and that the accuracy of tests may be reduced if:**

- testing is carried out too early (before antibodies have developed)
- the person has reduced immunity, for example, people on immunosuppressant treatments, which might affect the development of antibodies.

**1.2.26 Advise people that tests from non-UKAS laboratories may not have been fully evaluated to diagnose Lyme disease.**

**1.2.27 Explain to people that:**

- the symptoms and signs associated with Lyme disease overlap with those of other conditions
- they will be assessed for alternative diagnoses if their tests are negative and their symptoms have not resolved
- symptoms such as tiredness, headache and muscle pain are common, and a specific medical cause is often not found.

To find out why the committee made the recommendations on information, see [rationale and impact](#).

## 1.3 Management

### Emergency referral

- 1.3.1 Follow usual clinical practice for emergency referrals, for example, in people with symptoms that suggest central nervous system infection, uveitis or cardiac complications such as complete heart block, even if Lyme disease is suspected.

### Specialist advice

- 1.3.2 Discuss the diagnosis and management of Lyme disease in children and young people under 18 years with a specialist, unless they have a single erythema migrans lesion and no other symptoms. Choose a specialist appropriate for the child or young person's symptoms dependent on availability, for example, a paediatrician, paediatric infectious disease specialist or a paediatric neurologist.
- 1.3.3 If an adult with Lyme disease has focal symptoms, consider a discussion with or referral to a specialist, without delaying treatment. Choose a specialist appropriate for the person's symptoms, for example, an adult infection specialist, rheumatologist or neurologist.

To find out why the committee made the recommendations on emergency referral and specialist advice and how they might affect practice, see [rationale and impact](#).

## Antibiotic treatment

- 1.3.4 For adults and young people (aged 12 and over) diagnosed with Lyme disease, offer antibiotic treatment according to their symptoms as described in table 1.
- 1.3.5 For children (under 12) diagnosed with Lyme disease, offer antibiotic treatment according to their symptoms as described in table 2.
- 1.3.6 Ask women (including young women under 18) if they might be pregnant before offering antibiotic treatment for Lyme disease (see [recommendation 1.3.18](#) on treatment in pregnancy).
- 1.3.7 If symptoms worsen during treatment for Lyme disease, assess for an allergic reaction to the antibiotic. Be aware that a [Jarisch–Herxheimer reaction](#) may cause an exacerbation of symptoms but does not usually warrant stopping treatment.
- 1.3.8 Consider clinical review during or after treatment for Lyme disease to assess for possible side effects and response to treatment.

**Table 1 Antibiotic treatment for Lyme disease in adults and young people (aged 12 and over) according to symptoms<sup>a</sup>**

Symptoms	Treatment	First alternative	Second alternative
<b>Lyme disease without focal symptoms</b>			
Erythema migrans and/or Non-focal symptoms	Oral doxycycline: 100 mg twice per day or 200 mg once per day for 21 days	Oral amoxicillin: 1 g 3 times per day for 21 days	Oral azithromycin <sup>b</sup> : 500 mg daily for 17 days
<b>Lyme disease with focal symptoms</b>			
Lyme disease affecting the cranial nerves or peripheral nervous system	Oral doxycycline: 100 mg twice per day or 200 mg once per day for 21 days	Oral amoxicillin: 1 g 3 times per day for 21 days	–

Lyme disease affecting the central nervous system	Intravenous ceftriaxone: 2 g twice per day or 4 g once per day for 21 days (when an oral switch is being considered, use doxycycline)	Oral doxycycline: 200 mg twice per day or 400 mg once per day for 21 days	–
Lyme disease arthritis	Oral doxycycline: 100 mg twice per day or 200 mg once per day for 28 days	Oral amoxicillin: 1 g 3 times per day for 28 days	Intravenous ceftriaxone: 2 g once per day for 28 days
Acrodermatitis chronica atrophicans			
Lyme carditis <sup>b</sup>	Oral doxycycline: 100 mg twice per day or 200 mg once per day for 21 days	Intravenous ceftriaxone: 2 g once per day for 21 days	–
Lyme carditis and haemodynamically unstable	Intravenous ceftriaxone: 2 g once per day for 21 days (when an oral switch is being considered, use doxycycline)	–	–
<sup>a</sup> For Lyme disease suspected during pregnancy, use appropriate antibiotics for stage of pregnancy. <sup>b</sup> Do not use azithromycin to treat people with cardiac abnormalities associated with Lyme disease because of its effect on QT interval.			

Table 2 Antibiotic treatment for Lyme disease in children (under 12) according to symptoms<sup>a,b,c</sup>

Symptoms	Age	Treatment	First alternative	Second alternative
Lyme disease without focal symptoms				

Erythema migrans and/or Non-focal symptoms	9–12 years	Oral doxycycline <sup>a</sup> for children under 45 kg: 5 mg/kg in 2 divided doses on day 1 followed by 2.5 mg/kg daily in 1 or 2 divided doses for a total of 21 days  For severe infections, up to 5 mg/kg daily for 21 days	Oral amoxicillin for children 33 kg and under: 30 mg/kg 3 times per day for 21 days	Oral azithromycin <sup>d,</sup> <sup>e</sup> for children 50 kg and under: 10 mg/kg daily for 17 days
	Under 9	Oral amoxicillin for children 33 kg and under: 30 mg/kg 3 times per day for 21 days	Oral azithromycin <sup>d,e</sup> for children 50 kg and under: 10 mg/kg daily for 17 days	–
<b>Lyme disease with focal symptoms</b>				
Lyme disease affecting the cranial nerves or peripheral nervous system	9–12 years	Oral doxycycline <sup>a</sup> for children under 45 kg: 5 mg/kg in 2 divided doses on day 1 followed by 2.5 mg/kg daily in 1 or 2 divided doses for a total of 21 days  For severe infections, up to 5 mg/kg daily for 21 days	Oral amoxicillin for children 33 kg and under: 30 mg/kg 3 times per day for 21 days	–
	Under 9	Oral amoxicillin for children 33 kg and under: 30 mg/kg 3 times per day for 21 days	–	–

Lyme disease affecting the central nervous system	9–12 years	Intravenous ceftriaxone for children 50 kg and under: 80 mg/kg once per day for 21 days	Oral doxycycline <sup>a</sup> for children under 45 kg: 5 mg/kg in 2 divided doses on day 1 followed by 2.5 mg/kg daily in 1 or 2 divided doses for a total of 21 days  For severe infections, up to 5 mg/kg daily	–
	Under 9	Intravenous ceftriaxone for children 50 kg and under: 80 mg/kg once per day for 21 days	–	–
Lyme arthritis or Acrodermatitis chronica atrophicans	9–12 years	Oral doxycycline <sup>a</sup> for children under 45 kg: 5 mg/kg in 2 divided doses on day 1 followed by 2.5 mg/kg daily in 1 or 2 divided doses for a total of 28 days  For severe infections, up to 5 mg/kg daily for 21 days	Oral amoxicillin for children 33 kg and under: 30 mg/kg 3 times per day 28 days	Intravenous ceftriaxone for children 50 kg and under: 80 mg/kg once per day for 28 days
	Under 9	Oral amoxicillin for children, 33 kg and under: 30 mg/kg 3 times per day for 28 days	Intravenous ceftriaxone for children 50 kg and under: 80 mg/kg once per day for 28 days	–



Lyme carditis (both haemodynamically stable and unstable) <sup>e</sup>	9–12 years	Oral doxycycline <sup>a</sup> for children under 45 kg: 5 mg/kg in 2 divided doses on day 1 followed by 2.5 mg/kg daily in 1 or 2 divided doses for a total of 21 days  For severe infections, up to 5 mg/kg daily for 21 days	Intravenous ceftriaxone for children 50 kg and under: 80 mg/kg once per day for 21 days	–
	Under 9	Intravenous ceftriaxone for children 50 kg and under: 80 mg/kg once per day for 21 days	–	–

<sup>a</sup> At the time of publication (April 2018), doxycycline did not have a UK marketing authorisation for this indication in children under 12 years and is contraindicated. The use of doxycycline for children aged 9 years and above in infections where doxycycline is considered first line in adult practice is accepted specialist practice. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>b</sup> Discuss management of Lyme disease in children and young people with a specialist, unless they have a single erythema migrans lesion with no other symptoms, see [recommendation 1.3.2](#).

<sup>c</sup> Children weighing more than the amounts specified should be treated according to table 1.

<sup>d</sup> At the time of publication (April 2018), azithromycin did not have a UK marketing authorisation for this indication in children under 12 years. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's [Prescribing guidance: prescribing unlicensed medicines](#) for further information.

<sup>e</sup> Do not use azithromycin to treat people with cardiac abnormalities associated with Lyme disease because of its effect on QT interval.

To find out why the committee made the recommendations on antibiotic treatment and how they might affect practice, see [rationale and impact](#).

## Ongoing symptoms after a course of antibiotics

- 1.3.9 If symptoms that may be related to Lyme disease persist, do not continue to improve or worsen after antibiotic treatment, review the person's history and symptoms to explore:
- possible alternative causes of the symptoms
  - if re-infection may have occurred
  - if treatment may have failed
  - details of any previous treatment, including whether the course of antibiotics was completed without interruption
  - if symptoms may be related to organ damage caused by Lyme disease, for example, nerve palsy.
- 1.3.10 If the person's history suggests re-infection, offer antibiotic treatment for Lyme disease according to their symptoms (see tables 1 and 2).
- 1.3.11 Consider a second course of antibiotics for people with ongoing symptoms if treatment may have failed. Use an alternative antibiotic to the initial course, for example, for adults with Lyme disease and arthritis, offer amoxicillin if the person has completed an initial course of doxycycline.
- 1.3.12 If a person has ongoing symptoms following 2 completed courses of antibiotics for Lyme disease:
- do not routinely offer further antibiotics and
  - consider discussion with a national reference laboratory or discussion or referral to a specialist as outlined in [recommendation 1.2.20](#).
- 1.3.13 Explain to people with ongoing symptoms following antibiotic treatment for Lyme disease that:

- continuing symptoms may not mean they still have an active infection
- symptoms of Lyme disease may take months or years to resolve even after treatment
- some symptoms may be a consequence of permanent damage from infection
- there is no test to assess for active infection and an alternative diagnosis may explain their symptoms.

To find out why the committee made the recommendations on ongoing symptoms after a course of antibiotics and how they might affect practice, see [rationale and impact](#).

## Non-antibiotic management of ongoing symptoms

- 1.3.14 Offer regular clinical review and reassessment to people with ongoing symptoms, including people who have no confirmed diagnosis.
- 1.3.15 Explore any ongoing symptoms with the person and offer additional treatment if needed following usual clinical practice.
- 1.3.16 Be alert to the possibility of symptoms related to Lyme disease that may need assessment and management, including:
- chronic pain
  - depression and anxiety (see NICE's guideline on [common mental health problems](#))
  - fatigue
  - sleep disturbance.
- 1.3.17 Support people who have ongoing symptoms after treatment for Lyme disease by:
- encouraging and helping them to access additional services, including referring to adult social care for a care and support needs assessment, if they would benefit from these
  - communicating with children and families' social care, schools and higher education, and employers about the person's need for a gradual return to activities, if relevant.

To find out why the committee made the recommendations on non-antibiotic management of ongoing symptoms and how they might affect practice, see [rationale and impact](#).

## Management for women with Lyme disease during pregnancy and their babies

- 1.3.18 Assess and diagnose Lyme disease during pregnancy in the same way as for people who are not pregnant. Treat Lyme disease in pregnant women using appropriate antibiotics for the stage of pregnancy<sup>[1]</sup>.
- 1.3.19 Tell women with Lyme disease during pregnancy that they are unlikely to pass the infection to their baby and emphasise the importance of completing the full course of antibiotic treatment.
- 1.3.20 Advise women who had Lyme disease during pregnancy to tell this to their healthcare professional if they have any concerns about their baby. In this situation, healthcare professionals should discuss the history with a paediatric infectious disease specialist and seek advice on what investigations to perform.
- 1.3.21 Start treatment for Lyme disease under specialist care for babies of women treated for Lyme disease during pregnancy if the baby has IgM antibodies specific for Lyme disease or there is any suspicion the baby may be infected.

To find out why the committee made the recommendations on management for women with Lyme disease during pregnancy and their babies and how they might affect practice, see [rationale and impact](#).

## 1.4 Information for people with Lyme disease

- 1.4.1 Explain to people diagnosed with Lyme disease that:
- Lyme disease is a bacterial infection treated with antibiotics
  - most people recover completely
  - prompt antibiotic treatment reduces the risk of further symptoms developing and increases the chance of complete recovery

- it may take time to get better, but their symptoms should continue to improve in the months after antibiotic treatment
- they may need additional treatment for symptom relief.

1.4.2 Tell people who are starting antibiotics for Lyme disease that some people may have a Jarisch–Herxheimer reaction to treatment. Explain that:

- this causes a worsening of symptoms early in treatment
- it can happen when large numbers of bacteria in the body are killed
- it does not happen to everyone treated for Lyme disease
- they should contact their doctor and keep taking their antibiotics if their symptoms worsen.

1.4.3 Advise people with Lyme disease to talk to their doctor if their symptoms have not improved or if symptoms return after completing treatment.

1.4.4 Explain to people with Lyme disease that infection does not give them lifelong immunity and that it is possible for them to be re-infected and develop Lyme disease again.

To find out why the committee made the recommendations on information, see [rationale and impact](#).

## *Terms used in this guideline*

### **Test for Lyme disease**

Lyme disease is caused by infection with bacteria from different species of *Borrelia*. The majority of tests for Lyme disease detect antibodies produced in response to infection by bacteria.

The term Lyme disease is used when referring to both the disease and to tests for an antibody response. This reflects the terminology used in clinical practice.

## Jarisch–Herxheimer reaction

This is a systemic reaction, thought to be caused by the release of cytokines when antibiotics kill large numbers of bacteria. Symptoms include a worsening of fever, chills, muscle pains and headache. The reaction can start between 1 and 12 hours after antibiotics are started but can also occur later and can last for a few hours or 1 or 2 days. The reaction is self-limiting and usually resolves within 24 to 48 hours.

It was originally reported in the treatment of syphilis but has been documented in tick-borne diseases including Lyme disease, leptospirosis and relapsing fever.

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<sup>[1]</sup> See the [BNF](#) for more information on antibiotics during pregnancy.

## Recommendations for research

The guideline committee has made the following recommendations for research.

### *1 Core outcome set for studies of management of Lyme disease*

Can a core outcome set be developed for clinical trials of management of Lyme disease?

#### Why this is important

Antibiotic treatment is the mainstay of management for Lyme disease. The studies published on the management of Lyme disease use differing outcomes, which are often poorly defined. The development of a core outcome set has been identified as a high priority because it would allow comparison across trials and allow appropriate meta-analysis to strengthen results. The methods used should be patient-focused and include patient input on priority outcomes and how they should be measured.

### *2 Clinical epidemiology of Lyme disease in the UK*

What are the incidence, presenting features, management and outcome of Lyme disease in the UK?

#### Why this is important

There is a lack of robust epidemiological data on Lyme disease in the UK population. A large clinico-epidemiological study to collect data on incidence, presenting clinical features, management and outcome of Lyme disease in community and hospital settings in the UK would generate population-based statistics. These statistics would enable interventions such as antibiotic treatment and service improvements to be assessed properly and for services to be tailored so they best serve people with Lyme disease; this was felt to be of high priority. There is no current requirement to notify cases of Lyme disease; therefore, current data are likely to underestimate the number of cases.

### *3 Seroprevalence of Lyme disease-specific antibodies and other tick-borne infections in the UK population*

What is the current seroprevalence of Lyme disease-specific antibodies and other tick-borne infections in people in the UK?

## Why this is important

This information is not currently available and is of high priority. Without understanding the underlying population's seroprevalence of Lyme disease-specific antibodies in the UK, it is impossible to interpret incidence data accurately or to understand fully the epidemiology of Lyme disease in the UK. The available data suggest there are areas of higher and lower prevalence in the UK but there are many gaps in knowledge. This study is needed to act as a basis for future studies. The information may also help interpret serology of individuals living in endemic areas where positive serological results may be more common and may not always indicate an acute or recent infection.

Data now may also act as a baseline to help determine whether Lyme disease is spreading and becoming more common. This will be of benefit to patients affected by Lyme disease and healthcare workers treating it in the UK. Many people are concerned about the possible presence of co-infections transmitted by ticks; these are thought to be rare in the UK (compared with other parts of the world) but there are insufficient data to confirm or refute this. Better evidence may improve diagnostic and treatment decisions.

## *4 Antimicrobial management of Lyme disease*

What are the most clinically and cost-effective treatment options for different clinical presentations of Lyme disease in the UK?

## Why this is important

The evidence on the effectiveness of antimicrobial treatment regimens used in different presentations of Lyme diseases is of poor quality, out-dated and often based on small studies. No relevant cost-effectiveness evidence was identified. A series of prospective multicentre studies is needed to compare the clinical and cost effectiveness of different dosages and length of treatments needed and the clinical and cost effectiveness of oral compared with intravenous treatments for different presentations of Lyme disease. This is felt to be of high priority because it has enormous implications for people with Lyme disease and for NHS costs.

There is currently insufficient quality evidence on the most effective drug and dose, and the effectiveness of extended treatment or retreatment regimens in those with continuing symptoms remains uncertain, leading to multiple referrals in search of alternative diagnoses. Clarification could improve outcomes, reduce costs and may minimise unnecessary treatment.



## *5 Laboratory tests to diagnose initial and ongoing infection and determine re-infection in the different presentations of Lyme disease in the UK*

What is the most clinically and cost-effective serological antibody-based test, biomarker or other test for diagnosing Lyme disease in the UK at all stages, including re-infection?

### **Why this is important**

Determining the most clinically and cost-effective diagnostic tests for Lyme disease will improve patient care and is a high priority. The clinical presentation of Lyme disease is variable with the diagnosis of all presentations, except erythema migrans, relying in part on laboratory testing. Current literature suggests that a combined IgG/IgM enzyme-linked immunosorbent assay (ELISA) based on the IR6 peptide and immunoblot are useful; however, published evidence is of either low or very low quality and is not UK based. There is evidence of variation in the IR6 peptide between the principal *Borrelia* genospecies in UK ticks and a combination of ELISAs may improve sensitivity.

A 'test of cure' for Lyme disease does not exist and, consistent with most other infectious diseases, serology is likely to remain positive for some time following successful treatment of infection in most patients. However, little is known about the evolution of antibody titres over time in those who have been treated successfully and in those who have ongoing symptoms.

It is frequently stated that early antibiotic treatment of Lyme disease abrogates the immune response, so that serology remains or becomes negative. This is not a common occurrence in other infections but there are inadequate prospective data on whether it occurs in people with Lyme disease. Observational studies to clarify this would be helpful. In addition, understanding the natural course of Lyme disease serology, and non-serological tests over time, may assist in the interpretation of test results in patients who remain symptomatic and in those who are high risk for re-infection, such as those with occupational exposure.

In particular, further research into the value of novel biomarkers (for example, CXCL13 and others) and other types of tests may be helpful to support the current low-quality evidence. The examples of tests included in this research recommendation reflect those included in this guideline. However, other novel biomarkers are likely to be developed and require similar assessment.

## Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice. They link to details of the evidence and a full description of the committee's discussion.

### *Awareness of Lyme disease*

Recommendations [1.1.1 to 1.1.3](#)

#### Why the committee made the recommendations

The committee agreed that raising awareness is important to improve diagnosis and management of Lyme disease. Based on the committee's knowledge and experience, and some limited evidence on UK incidence, they agreed to highlight how infection occurs, typical tick habitats and areas of higher risk. This may help to guide healthcare professionals, for example, in recognising the possibility of Lyme disease when a person is unaware that they have been bitten by a tick or in areas where ticks are found but Lyme disease is not highly prevalent.

The committee also agreed that people who may have been exposed to ticks should be given advice to help avoid Lyme disease in the future.

Because of the lack of evidence in this area, the committee also developed a research recommendation on the clinical epidemiology of Lyme disease in the UK (see [research recommendation 2](#)).

#### How the recommendations might affect practice

The recommendations aim to improve awareness of Lyme disease, to promote early investigation and treatment, and to optimise outcomes in people with Lyme disease. They will change current practice by prompting healthcare professionals to think about the possibility of Lyme disease. This may result in an increase in testing and treatment, but the cost of this is likely to be balanced by the benefits of improved recognition and early treatment.

Full details of the evidence and the committee's discussion are in [evidence review A: awareness of Lyme disease](#).

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## *Clinical assessment*

Recommendations [1.2.1 to 1.2.10](#)

### **Why the committee made the recommendations**

The committee reviewed evidence on the diagnostic accuracy of some specific signs and symptoms (erythema migrans, facial palsy, lymphocytoma, acrodermatitis chronica atrophicans and heart block or arrhythmias) to assess if any could be used to diagnose Lyme disease or to indicate that testing should be carried out.

Erythema migrans only occurs in Lyme disease and may be used to diagnose Lyme disease. The committee agreed that the evidence, although limited, supported this. Some healthcare professionals may not be familiar with erythema migrans, so a description of the rash and its characteristics was included.

Lyme disease has a varied presentation and erythema migrans is not always present, so the assessment of other signs and symptoms is important. The evidence was not strong enough for the committee to recommend diagnosis, testing or treatment based on any other symptom or sign alone. However, the committee noted a number of potential presentations of Lyme disease that should alert healthcare professionals to consider the possibility of Lyme disease and prompt a discussion about the possibility of tick exposure. Based on their knowledge and experience, the committee agreed to highlight factors to consider in history and presentation to help with clinical decision-making.

### **How the recommendations might affect practice**

Current practice is to diagnose and treat Lyme disease in people with erythema migrans. People who present without erythema migrans but whose history and presentation are consistent with Lyme disease are offered testing. The recommendations will not change current practice but should serve as a reminder to healthcare professionals, particularly in areas where Lyme disease is less common, to think about Lyme disease as a differential diagnosis. Implementing these recommendations is unlikely to involve additional costs and may improve recognition and diagnosis.

Full details of the evidence and the committee's discussion are in [evidence review B: diagnostic accuracy of signs and symptoms](#).

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## *Laboratory investigations*

Recommendations [1.2.11](#) to [1.2.23](#)

### **Why the committee made the recommendations**

The committee agreed that laboratory testing is unnecessary for people presenting with erythema migrans, because the rash is very specific to Lyme disease and prompt treatment will prevent further symptoms developing. However, most other symptoms associated with Lyme disease have other more common causes, so testing may be helpful to ensure accurate diagnosis and appropriate treatment.

Based on the evidence on test accuracy, the committee agreed that test results need careful interpretation alongside clinical assessment to guide diagnosis. Because of the limitations of tests, Lyme disease should not be ruled out by negative tests if it is strongly suggested by the clinical assessment. The committee decided that treatment could be started at the same time as testing if clinical assessment strongly suggests Lyme disease because prompt treatment is important.

The committee agreed a strategy of 2-tier testing (an initial and confirmatory test), which the evidence indicated was potentially cost saving. Initial testing with a combination IgM and IgG enzyme-linked immunosorbent assay (ELISA) for Lyme disease should be offered because the evidence generally showed better accuracy (both sensitivity and specificity) for combined tests compared to IgM-only and IgG-only tests. The evidence was best for tests based on purified or recombinant antigens derived from the VlsE protein or its IR6 domain peptide (such as a C6).

For people with a negative ELISA result who continue to have symptoms, the committee agreed that clinical review would ensure that alternative diagnoses are not missed. In addition, because antibodies take some time to develop, repeat testing would be warranted for people who may have had the initial test too early, before an immune response has developed. If symptoms have been present for 12 weeks, the committee agreed that an immunoblot would help rule out or confirm diagnosis where uncertainty still remains.

The committee agreed that for people with negative test results who continue to have symptoms, discussion with or referral to a specialist for further review might be beneficial.

The committee agreed that testing should be done in UKAS-accredited laboratories and that any tests used for diagnosis should be validated before they are used to diagnose Lyme disease to avoid unreliable and misleading results, which may lead to misdiagnosis.

Based on their knowledge and experience, the committee agreed that *Borrelia burgdorferi sensu lato* (sl) infection does not behave differently in children than adults, but acknowledged that a young child's immune responses might not be as rapid and effective. The limited evidence in children did not show a noticeable difference in test accuracy compared with adults. Therefore, the committee decided that separate recommendations for testing in children were unnecessary.

The committee considered it important that people being tested for Lyme disease understand how the tests work, their limitations and the importance of basing decisions on tests that are valid.

The committee noted that further research would be helpful to determine the seroprevalence of antibodies to tick-borne infections in the UK and to clarify further the most effective tests at different stages of Lyme disease (see [research recommendation 3](#) and [research recommendation 5](#)).

## How the recommendations might affect practice

A 2-tiered testing system is used in current practice, in which a positive result on an initial ELISA leads to a confirmatory immunoblot test. A negative result on an initial ELISA would not usually lead to a confirmatory immunoblot test. Therefore, the recommendation to carry out an immunoblot test, despite an initial negative ELISA when there is clinical suspicion of Lyme disease would be a change to practice and increase the number of people receiving this test. However, this would only apply to a small population, so this recommendation is not likely to have a significant resource impact.

Full details of the evidence and the committee's discussion are in [evidence review C: diagnostic tests](#).

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## Emergency referral and specialist advice

Recommendations [1.3.1](#) to [1.3.3](#)

## Why the committee made the recommendations

Lyme disease will not usually be considered as the most likely cause when people present with neurological and other symptoms that need emergency referral (such as central nervous system infection or heart block). However, the committee wanted to emphasise that if the history and physical findings suggest Lyme disease, usual clinical practice is still appropriate, because people

may need additional supportive treatment from specialist services as well as appropriate antibiotics.

The type of problems that children with Lyme disease may develop, such as arthritis or facial palsy, are uncommon and the committee decided to recommend that management for children and young people with presentations other than uncomplicated erythema migrans (a single lesion with no other symptoms) should be discussed with a specialist to ensure the diagnosis is correct and for advice on antibiotic treatment.

For adults with focal symptoms such as arthritis, the committee agreed that a discussion with a specialist may be considered, but that treatment can be started.

## How the recommendations might affect practice

People who are systemically unwell with neurological or cardiac disease are referred to hospital for urgent treatment, so this recommendation should not lead to a change in existing practice.

The occurrence of symptoms such as arthritis and facial palsy are uncommon in children, so it is expected that most children with these symptoms are already seen in specialist services; therefore, this recommendation should not result in a large change of practice.

Full details of the evidence and the committee's discussion are in [evidence review D: management of erythema migrans](#).

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## *Antibiotic treatment*

Recommendations [1.3.4](#) to [1.3.8](#)

## Why the committee made the recommendations

### *Erythema migrans*

A number of studies examined antibiotic treatment of Lyme disease with erythema migrans using different antibiotics, doses and durations of treatment. However, many of the studies did not reflect current prescribing practices and the evidence was of poor quality.

For adults, there was evidence that doxycycline is more clinically effective than some other antibiotics. However, the evidence showed no clear difference in effectiveness between doxycycline, an amoxicillin/probenecid combination and azithromycin. The evidence also showed no benefit of intravenous or intramuscular cephalosporin over doxycycline. It was noted that doxycycline and amoxicillin are able to penetrate the blood–cerebrospinal fluid barrier and pass into the central nervous system, whereas azithromycin cannot. This may be important to prevent the development of further symptoms. Doxycycline can also be taken in a single daily dose, which may help with adherence.

Based on these factors, along with their knowledge and experience, the committee agreed on doxycycline as the initial treatment for adults and young people (aged 12 and over), with amoxicillin as an alternative, and azithromycin as a third option when both doxycycline and amoxicillin are contraindicated.

The committee acknowledged that infectious disease specialists currently treat Lyme disease in children aged 9 and above with doxycycline, although it is not licensed in the UK for children under 12, and it is contraindicated in this age group because of side effects, such as teeth staining. Based on their experience and knowledge, feedback from stakeholders, and the evidence for adults, the committee agreed that doxycycline is the most effective treatment for Lyme disease and that the risk of dental problems in children is low when it is used for short-term treatment (28 days or less). Therefore, doxycycline can be used as the initial treatment for Lyme disease in children aged 9 and above. The committee agreed on doxycycline doses based on their knowledge and experience of current practice both in the UK and the US.

The use of doxycycline in children under 9 years is currently limited by licensing and clinical experience. There was some evidence that amoxicillin and azithromycin were equally effective in children. Because of its ability to penetrate the blood–cerebrospinal fluid barrier, the committee agreed that children under 9 should be offered amoxicillin as the initial treatment, with azithromycin as an alternative treatment option, and that doses should be adjusted by weight.

Current guidelines give ranges for treatment duration, generally between 10 and 21 days, without guidance on when to use a longer or shorter course. The committee agreed that this is not clear enough for generalists. The evidence for treatment duration was limited. The committee decided that longer courses of 21 days of treatment should be offered as standard because of their concern at low cure rates in some studies and the lack of clear evidence for shorter courses. They also agreed that a longer course may be reassuring for people being treated for Lyme disease who continue to have symptoms. The evidence showed adverse event rates were not increased for longer courses.

The committee agreed that further research would be helpful, both to develop an outcome set for clinical trials and to determine the most effective treatment for different presentations of Lyme disease (see [research recommendation 1](#) and [research recommendation 4](#)).

Full details of the evidence and the committee's discussion are in [evidence review D: management of erythema migrans](#).

### ***Non-focal symptoms of Lyme disease***

No studies were identified comparing different antibiotics for managing Lyme disease in people with non-focal symptoms (symptoms such as fever, sweats and muscle pain, which are not specific to an organ system). However, the committee reviewed the evidence available for treating other symptoms and, based on this and their knowledge and experience, agreed that people with non-focal symptoms should be given the same treatment as people with erythema migrans.

Because of the uncertainties about diagnosis and management, the committee agreed that care of children and young people under 18 with Lyme disease and non-erythema migrans presentations should have their care discussed with a specialist.

Full details of the evidence and the committee's discussion are in [evidence review E: management of non-specific symptoms](#).

### ***Lyme disease affecting the cranial nerves, peripheral nervous system or central nervous system***

The evidence for antibiotic treatment of Lyme disease affecting the nervous system was limited. One study showed a greater benefit with oral doxycycline than intravenous ceftriaxone in treating Lyme disease affecting the peripheral nervous system. However, both treatments showed low rates of cure (full resolution of neurological symptoms). The committee also noted that the study used a 14-day course of antibiotics, which is below the maximum treatment durations recommended by some current guidelines.

The committee agreed that people presenting with meningitis or encephalitis (before a diagnosis of Lyme disease) would receive treatment with intravenous ceftriaxone, and that intravenous treatment would achieve adequate concentrations in the central nervous system more rapidly than oral treatment.

The committee also discussed the management of neurosyphilis, which has similar central nervous system involvement. The committee considered that, although the evidence was limited, central



nervous system symptoms in Lyme disease should be treated with a similar antibiotic dose to that recommended for neurosyphilis.

Once-daily ceftriaxone has the advantage of being given more easily as an outpatient treatment than other intravenous options, which allows completion of the course as an outpatient.

Taking these factors into account and based on their knowledge and experience, the committee agreed on a 21-day course of intravenous ceftriaxone 4 g daily as the initial treatment for adults and young people (aged 12 and over) with Lyme disease affecting the central nervous system, with a 21-day course of doxycycline 400 mg daily recommended as an alternative treatment. The higher dose is the recommended dose for bacterial meningitis. For Lyme disease affecting the cranial nerves or the peripheral nervous system, the committee agreed on a 21-day course of doxycycline 200 mg daily as the initial treatment for adults and young people (aged 12 and over), with amoxicillin recommended as an alternative treatment.

No studies were identified for nervous system symptoms in children. However, the committee agreed that the evidence for adults and young people could be used to support similar treatment for children aged 9 to 12 years, with the same antibiotics and duration of treatment but with doses adjusted by weight. The use of doxycycline in children under 9 years is currently limited by licensing and clinical experience.

Because of the importance of diagnosis and management, the committee also agreed that care of children and young people under 18 should be discussed with a specialist.

Full details of the evidence and the committee's discussion are in [evidence review F: management of neuroborreliosis](#).

### ***Lyme disease arthritis***

The studies identified looked at antibiotic treatment in children, young people and adults with Lyme arthritis (inflammation affecting 1 or more joints). Evidence from 1 study showed that a 30-day course of doxycycline resulted in fewer symptom relapses and adverse events than 30 days of amoxicillin plus probenecid.

The committee agreed that longer courses of treatment are appropriate when treating Lyme arthritis because it is difficult for antibiotics to penetrate to the synovium and synovial fluid.

Taking these factors into account, the committee decided that a 28-day course of antibiotics would be appropriate and also practical, because antibiotics are available in weekly packs.

Because the evidence was limited, the committee also took into account evidence for other presentations of Lyme disease. Based on this, along with their knowledge and experience of current practice, the committee agreed that doxycycline should be offered to adults and young people (aged 12 and over) as the initial treatment, with amoxicillin recommended as an alternative treatment. The committee also agreed that if oral doxycycline and amoxicillin are contraindicated or unsuitable, 28 days of intravenous ceftriaxone should be offered.

Although there was no evidence for treating Lyme arthritis in children, the committee agreed that the evidence for adults and young people could be used to support similar treatment for children aged 9 to 12 years, with the same antibiotics and duration of treatment but with doses adjusted by weight. The use of doxycycline in children under 9 years is currently limited by licensing and clinical experience.

Because of the importance of correct diagnosis and management, the committee agreed that care of children and young people under 18 with Lyme disease and non-erythema migrans presentations should be discussed with a specialist.

Full details of the evidence and the committee's discussion are in [evidence review G: management of arthritis](#).

### ***Acrodermatitis chronica atrophicans***

One study suggested that a 30-day course of doxycycline was better for treating acrodermatitis chronica atrophicans than a 20-day course of treatment. Oral doxycycline given for 30 days was also more effective than a 15-day course of intravenous ceftriaxone. The committee agreed that a longer course of treatment might be beneficial because it is difficult for antibiotics to penetrate the affected skin. They also took into account evidence for Lyme arthritis, which justified a longer treatment course to allow penetration into joints. The committee decided that a 28-day course of antibiotics would be appropriate and practical, because antibiotics are available in weekly packs.

The evidence for antibiotics was very limited, so the committee also took into account evidence for other presentations of Lyme disease and their experience and knowledge of current practice. The committee agreed that doxycycline should be offered to adults and young people (aged 12 and over) as the initial treatment, with amoxicillin recommended as an alternative treatment. The

committee also agreed that if oral doxycycline and amoxicillin are contraindicated or unsuitable, intravenous ceftriaxone could be offered.

Although there was no evidence for treating acrodermatitis chronica atrophicans in children, the committee agreed that the evidence for adults and young people could be used to support similar treatment for children aged 9 to 12 years, with the same antibiotics and duration of treatment but with doses adjusted by weight. The use of doxycycline in children under 9 years is currently limited by licensing and clinical experience.

Because of the importance of correct diagnosis and management, the committee agreed that care of children and young people under 18 with Lyme disease and non-erythema migrans presentations should be discussed with a specialist.

Full details of the evidence and the committee's discussion are in [evidence review H: management of acrodermatitis chronica atrophicans](#).

### ***Lyme carditis***

No studies of antibiotic treatment for heart problems caused by Lyme disease were identified. Therefore, the committee reviewed the evidence available for treating other symptoms of Lyme disease and used this, their experience of current practice and their knowledge of care for people with heart problems, to develop the recommendations.

The committee decided that a 21-day course of doxycycline would be appropriate as the initial treatment for adults and young people (aged 12 and over) with carditis who are stable, with a 21-day course of intravenous ceftriaxone recommended as an alternative treatment.

The committee noted that people with severe heart problems are likely to need treatment in hospital from cardiologists. They agreed that intravenous ceftriaxone for 21 days would therefore be suitable as the initial treatment for people with carditis who are haemodynamically unstable.

Because of the lack of evidence for treatment in children, the committee agreed that the evidence for adults and young people could be used to support similar treatment for children aged 9 to 12 years, with the same antibiotics and duration of treatment but with doses adjusted by weight. The use of doxycycline in children under 9 years is currently limited by licensing and clinical experience.

Because of the importance of correct diagnosis and management, the committee agreed that care of children and young people under 18 with Lyme disease and focal symptoms such as carditis should be discussed with a specialist.

The committee also noted that azithromycin should not be used to treat people with cardiac abnormalities because of its effect on the QT interval.

Full details of the evidence and the committee's discussion are in [evidence review I: management of carditis](#).

### ***Lymphocytoma***

No evidence was identified for the antibiotic treatment of lymphocytoma related to Lyme disease. Lymphocytoma is a very rare early presentation of Lyme disease and the committee agreed that most people presenting with lymphocytoma only would be referred for specialist investigation of lesions to establish the diagnosis. People with lymphocytoma and other symptoms of Lyme disease would receive treatment appropriate for their other symptoms on diagnosis. Therefore, they decided not to make a recommendation and that further research in this area was not a priority.

Full details of the evidence and the committee's discussion are in [evidence review J: management of lymphocytoma](#).

### ***Ocular symptoms***

No evidence was identified for the antibiotic treatment of non-neurological ocular symptoms related to Lyme disease. The committee agreed that people presenting with severe ocular symptoms would be referred for specialist investigation. The committee noted that it is difficult to diagnose Lyme disease as a cause of ocular symptoms unless there is a supportive history and other symptoms of Lyme disease, but that people with other symptoms of Lyme disease would receive treatment appropriate for their other symptoms on diagnosis. Therefore, they decided not to make a recommendation and that further research in this area was not a priority.

Full details of the evidence and the committee's discussion are in [evidence review K: management of ocular symptoms](#).

## How the recommendations might affect practice

The recommendations aim to standardise antibiotic treatment and to provide a consistent framework for good practice in managing Lyme disease. Overall, there may be changes to prescribing practices, but the impact is likely to be small.

Full details of the evidence and the committee's discussion are in the [evidence reviews](#).

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## *Ongoing symptoms after a course of antibiotics*

Recommendations [1.3.9](#) to [1.3.13](#)

## Why the committee made the recommendations

People who have had treatment for Lyme disease sometimes report ongoing symptoms. The cause is often not clear and includes re-infection, or organ damage caused by Lyme disease, which may take a long time to heal or may even be permanent.

The evidence available for treating ongoing symptoms did not show benefit from prolonged treatment with antibiotics. However, based on their knowledge and experience, the committee agreed that treatment failure could occur and that a second course of an alternative antibiotic might sometimes be appropriate. The committee noted the importance of considering alternative diagnoses to prevent inappropriate antibiotic treatment and misdiagnosis.

The committee agreed that people with ongoing symptoms should not routinely be offered more than 2 courses of antibiotics because of lack of evidence of benefit. However, discussion with a specialist or referral should be considered for some people, and discussion with the UK national reference laboratory might be helpful, for example, if a different tick-borne disease is possible.

People who have a slow recovery from Lyme disease may need additional support and access to social care. The committee agreed that it was important that healthcare professionals help people with long-term symptoms related to Lyme disease to access support if needed.

## How the recommendations might affect practice

Current treatment for Lyme disease is a single course of antibiotics. Treatment for ongoing symptoms is unclear and practice varies. Further antibiotic treatment is now recommended as an

option if persisting infection is a possibility. This will standardise practice, but may cause an increase in antibiotic prescribing in a small number of patients. The committee agreed that this change in practice would not result in a significant resource impact given the small number of people with treatment failure.

Full details of the evidence and the committee's discussion are in [evidence review L: management of ongoing symptoms](#).

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## *Non-antibiotic management of ongoing symptoms*

Recommendations [1.3.14 to 1.3.17](#)

### **Why the committee made the recommendations**

No specific evidence review was carried out to inform recommendations on support, referral to social services or the need to consider assessing and managing other symptoms related to Lyme disease, such as chronic pain, fatigue or depression. The committee, however, acknowledged that some people with Lyme disease experience a slow recovery and may need professional support. Some people with Lyme disease feel that their needs are not considered in an appropriate way. Based on their knowledge and clinical experience, the committee agreed that healthcare professionals should consider the possibility of such needs and provide support if needed, including regular review for people with ongoing symptoms.

### **How the recommendations might affect practice**

Some people with Lyme disease may need support or social services, especially when they have a slow recovery. Social services needs assessments are carried out by local authorities and will not affect NHS practice.

Some people with Lyme disease may also present with related symptoms, such as chronic pain, depression or fatigue. Guidance for managing these symptoms already exists and therefore there will be no change to existing clinical practice.

Full details of the evidence and the committee's discussion are in [evidence review L: management of ongoing symptoms](#).

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## *Management for women with Lyme disease during pregnancy and their babies*

Recommendations [1.3.18 to 1.3.21](#)

### **Why the committee made the recommendations**

The committee acknowledged that mother-to-baby transmission of Lyme disease is possible in theory. There was an absence of evidence, but the risk appears to be very low. The committee decided that women could be reassured that pregnancy and their baby are unlikely to be affected, and highlighted the importance of completing treatment. It was also agreed that pregnant women should be treated following usual practice, but using antibiotics suitable in pregnancy.

Given the absence of evidence and the lack of a standard approach to care, the committee agreed that care of babies born to mothers with Lyme disease during pregnancy should be discussed with a paediatric infectious disease specialist if the mother has concerns about her baby. In addition, to ensure that babies with Lyme disease do not go untreated, the committee agreed that babies should receive treatment if they have serology showing IgM antibodies specific to Lyme disease or symptoms that might be caused by Lyme disease.

The committee agreed that more evidence on Lyme disease in pregnancy would be helpful to inform future guidance. Pregnant women with Lyme disease or suspected Lyme disease are a population of particular interest in the research recommendation on the clinical epidemiology of Lyme disease in the UK (see [research recommendation 2](#)).

No evidence was found for transmission of Lyme disease through sexual contact or blood products and the committee agreed that they could not make recommendations in these areas.

### **How the recommendations might affect practice**

There is no standardised approach to the care of babies born to mothers who had Lyme disease in pregnancy. The recommendations are unlikely to have a big impact on practice, but should reduce variation and provide guidance to reassure women and healthcare professionals.

Full details of the evidence and the committee's discussion are in [evidence review M: transmission](#).

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## *Information for people with Lyme disease*

Recommendations [1.2.24 to 1.2.27](#) and [1.4.1 to 1.4.4](#)

### **Why the committee made the recommendations**

There was a lack of evidence identified on the information needs of people with suspected or confirmed Lyme disease, or specific Lyme disease presentations. However, some evidence was identified that highlighted the need for information addressing the medical uncertainties of Lyme disease.

The guideline committee used this evidence, the evidence reviews on diagnosis and management, and their experience to make recommendations to inform people being investigated for and diagnosed with Lyme disease. The committee agreed that people would benefit from a better understanding of the nature of Lyme disease, the accuracy and limitations of testing, and issues with treatment and follow-up.

### **How the recommendations might affect practice**

The recommendations standardise and reinforce current good practice. Many healthcare professionals will not need to change their current practice.

Full details of the evidence and the committee's discussion are in [evidence review N: information needs](#).

Return to recommendations [1.2.24 to 1.2.27](#) and [1.4.1 to 1.4.4](#).



## Context

Lyme disease (Lyme borreliosis) is a tick-borne infectious disease. It is caused by different genospecies of *Borrelia* including *B. burgdorferi sensu strictu* (ss), *B. afzelii* and *B. garinii*, which can be transmitted to humans through a bite from an infected tick. Infection is more likely the longer a tick is attached to the skin. Ticks live in grassy and wooded areas, both in rural and urban locations. People who spend time in these areas for work or recreation are at increased risk of tick exposure.

Lyme disease can occur anywhere in the UK, although some areas have a higher reported incidence. Approximately 50% of laboratory-confirmed cases are diagnosed in the South East and South West of England. High incidence is also reported in Scotland. Worldwide, Lyme disease occurs mainly in the northern hemisphere, and travellers to areas of Europe, North America and elsewhere may be at risk. However, the true incidence of Lyme disease is unknown.

Although the disease has been recognised in mainland Europe for more than a century, it was first reported in England and Wales in the 1980s. Public Health England (PHE) reports that there are approximately 1,000 serologically confirmed cases of Lyme disease each year in England and Wales. Many diagnoses will also be made clinically without laboratory testing. The true number of cases is currently unknown.

In England and Wales, cases of laboratory-confirmed Lyme disease have increased. It is not certain how much of the rise is due to increased awareness and how much to the spread of the disease.

Infection with *B. burgdorferi sensu lato* (sl) can sometimes go unremarked, with mild symptoms that are ignored by the person. When symptoms occur, this is called Lyme disease. Many people may not notice or remember a tick bite. A bite can be followed by an 'erythema migrans' rash, which is sometimes mistaken for cellulitis or ringworm, and effective treatment is delayed. If there is no erythema migrans or it is unnoticed, diagnosis can be difficult because the same symptoms may be caused by many other conditions as well as Lyme disease.

The terminology around Lyme disease is varied and many poorly defined terms are used in the literature (such as chronic Lyme disease and post-Lyme disease). This guideline has avoided using controversial definitions and has concentrated on providing advice on diagnosis and treatment based on the available evidence, according to the clinical context, presentation, symptoms and available treatments. The guideline committee has noted the poor-quality evidence available on both diagnosis and treatment.

The guideline aims to raise awareness of when Lyme disease should be suspected and to ensure that people with suspected Lyme disease are given early and consistent treatment. The guideline committee has also developed a series of research recommendations to improve basic epidemiology, understanding of the natural history of Lyme disease, and to develop diagnostic tests appropriate for UK infections.

## Finding more information and resources

You can see everything NICE says on this topic in our interactive flowchart on [Lyme disease](#).

To find out what NICE has said on topics related to this guideline, see our web page on [infections](#).

For full details of the evidence and the guideline committee's discussions, see the [evidence reviews](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources](#) to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see [putting recommendations into practice: quick tips](#).

## Update information

### Minor changes since publication

**May 2018:** The definition for the Jarisch–Herxheimer reaction was amended to clarify when the reaction can start.

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### *Accreditation*

