Lyme disease stakeholder scoping workshop

23 February 2016

Notes from group discussion

Scope details	Group 1	Group 2	Group 3
1.1 Who is the focus: **Groups that will be covered:** • Adults and children with a suspected or confirmed diagnosis of Lyme disease	• The group suggested that the following groups might be split into different subgroups due to the difference in how they initially present with Lyme disease: – People with more than one condition – Pregnant women – Children under 2 (neuro borrelia) – People who are immunocompromised – People who have previously had Lyme disease – Congenital Lyme	• No comments	• Chronic/late - terms are not helpful. Suggested: post treatment Lyme disease syndrome. However people don't like the term syndrome • Avoid using the term chronic Lyme • Late Lyme can be meningitis, encephalitis, arthritis, chronic fatigue. • Definitions are generally inconsistent. • Other groups are those that respond to antibiotics/don't respond to antibiotics, immunosuppressed, pregnant women. People can be put into categories • Suggestion to list main presenting symptoms then look at treatment approaches and what the criteria for different types of treatment are.
1.2. Settings • All setting where NHS care	• No comments	• No comments	• No comments

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is provided or commissioned			
1.3 Key areas that will be covered • Assessment [history and examination] • Diagnosis [first line investigations and confirmatory tests] • Management [treatment for early and late Lyme disease] • Transmission **Areas that will not be covered** • Management of confirmed non-*Borrelia* diagnosis • Management of a confirmed diagnosis of chronic fatigue syndrome	**Key areas that will be covered** • The group suggested that re-evaluation might be added to this group, with GPs following up. **Key areas that will not be covered** • The group agreed that if chronic fatigue syndrome was in this list then so should fibromyalgia, and other related NICE guidance on management	• No comments	• No comments
1.4 Economic aspects	• It was noted that as there are so many different investigations for Lyme disease, that healthcare professionals needed to be more	• No comments	• No comments

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	definitive and confident, as there can be misdiagnosis with the general mind-set that Lyme disease is too rare. • There is a lack of access to appropriate tests at clinical presentation, so this could be something to consider.		

1.5 Key issues and questions
 	
Assessment
• In whom should Lyme disease be suspected?
  • Which symptoms or clinical signs should lead to diagnostic testing to confirm or rule out Lyme disease?
 	
Diagnosis
  • Which is the most clinically and cost effective test or combination of tests for diagnosing Lyme disease?
	Diagnosis
	• The group thought the list of diagnostic tests were good and thorough but wondered whether they would differentiate between different species. They also asked whether the tests go through accreditation.
	• The group agreed that definitions of newly-identified species should be included where possible, as this affects how the diagnostic tests can be interpreted.
	• The group agreed that the four main species diagnostic accuracy of tests should be evaluated for were:
		Diagnosis
		• The group wanted all available tests to be considered.
		• Interpretation of test results and diagnosis is an important issue.
		• Can Lyme disease be diagnosed without a positive test? There are cases where diagnostic tests are not needed (known tick bite and rash).
		• Erythema migrans can appear differently to the classic 'bull's eye'.
		• The scope could include tests and other investigations (e.g. nerve conduction studies).
		• Test limitations –
			Diagnosis
			• The group noted it would be important to look at the sensitivity and specificity of each test and there will be a need for consensus from the guideline committee to determine the gold standard.
			• Clinicians need to give guidance on sensitivity and specificity of each test available on NHS or others and for named tests there may be a need to refer to infectious diseases colleagues.
			• There are permutations and combinations of 20 pathogens for Lyme disease. What selection can

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Management • What is the best management strategy when there is a definite tick bite without symptoms? • What is the most clinically and cost effective treatment for early localised Lyme disease with an erythema migrans? • What is the most clinically and cost effective treatment for early localised Lyme disease without erythema migrans? • What is the most clinically and cost effective treatment for early disseminated Lyme disease without erythema migrans? • What is the most clinically and cost effective treatment for chronic Lyme disease of any	*Borrelia burgdorferi, Borrelia afzelii, Borrelia garinii, Borellia burgdorferi sensu stricto*. • The group also discussed that tests reporting a negative ELISA will not be send off by the labs, so this also needs clarification. • The group agreed that there needed to be definitions of what constitutes 'core' Lyme disease, so then it can be prioritised. • Scope needs separate definitions section, and the group were not sure what early localised presentation without a rash would actually be. • The group suggested that late Lyme disease would be no treatment in 4-6 months. • desirable to have a question to define prophylactic treatment. • Suggest looking at the International Lyme and Associated Diseases Society guideline for prevention and prophylactic treatment.	accuracy/interpretation may be different in special groups such as pregnant women and immunocompromised patients. • Tests should be carried out in the context of a patient's medical history. • There is an overreliance on testing – a combination of symptoms, history, diagnostic tests and other investigations should inform a diagnosis. • Clinical history will guide tests e.g. holidays to specific areas. GPs need to know which questions to ask. • If there are classic symptoms but negative test results, other available tests could be considered. • It is important to identify clinical situations for tests. The starting point is defining clinical groups. **Management** • The group noted a question: when someone has a definite tick bite	change the outcome? • The subdivisions of Lyme disease are under diagnosed e.g. if a person is immunosuppressed what is the effect of Lyme on this person, or do tests on this group of people manifest in different presentations? A question was asked: In pregnant women can Lyme disease be transmitted to the baby? • A diagnostic test for each patient with Lyme disease is not required if there are clinical circumstances e.g. if there is a migrans rash present. • With clinical presentations groups who need testing should be clear. and the epidemiology leading to algorithm in assessment should be clear. • In the UK NHS tests are only for 2 strains. Some people go and get tested elsewhere e.g. Germany/abroad if negative result in UK lab tests. The UK needs more

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manifestation: • In people who have not received treatment for Lyme disease? • In people whose symptoms recur after a treatment course is finished? • What is the most clinically and cost effective management strategy if symptoms persist after a treatment course is finished? **Transmission** • Can Lyme disease be transmitted from person to person?	**Transmission** • The group suggested that there might be another section to the transmission section regarding transmission through mosquitos and horseflies as there has been new evidence surrounding this.	without symptoms, should prophylaxis be given? • Suggestion to remove the term 'localised', and change to 'with localising symptoms'. • Localised means affecting one area e.g. erythema migrans or facial palsy. • Disseminated means symptoms move from one area to another e.g. erythema migrans then headache. • Early disseminated Lyme disease with erythema migrans highlighted as missing from the clinical categories. • 'Subjective symptoms' like general headache are much harder to assess/diagnose. • Cognitive symptoms are a separate category – they may be more subtle and more gradual. • Different treatment may be recommended for different clinical categories (e.g. cognitive, cardiac, neurological).	bands. There are different strains and there are 20 genomes of Borrelia. In overseas tests e.g. Germany they look at 20 bands. However bands are not a differential diagnosis and there are limitations of tests. There needs to be scoping of a wide range of tests and which bands considered to capture? • How long after symptoms should tests be done? Antibodies can take several weeks to manifest. • Tests useful to some however some people are falling through the net. • Clinical scores are used in private practice but not in the NHS. • We need to look at the cumulative evidence in different tests **Management** • A question was raised: What are the indications for intravenous (IV) or circumstances IV therapy or oral is given? There are randomised

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		• Severity may influence treatment duration. • Early Lyme can be defined as less than 6 months from tick bite/feeling unwell (most commonly tick bite or rash). • Late can be defined as more than 6 months from tick bite / feeling unwell. (Neurologic and cardiac symptoms usually occur between 4 and 8 weeks.) • There is uncertainty in identifying Lyme in approximately 1 in 5 patients; may be higher for children as the rash may appear on the scalp where it is not visible (ticks may bite higher on children as they are lower to the ground). • Time between tick bite and symptoms is variable. • Suggestion to change 'chronic' to 'late'. • Often patients see infectious disease specialists having already been to other specialists.	controlled trials investigating IV vs. oral • Usual agents are Doxycycline/amoxicillin/cefuroxime . What about 2 agents single or in combination? • What are the presentations for management? • Know contraindications – treat all infections – patient survey 60% had Lyme disease infection.

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		• Possible additional question noted: What is the best management strategy for patients with non-classic symptoms with positive/negative tests?	
Main outcomes • Quality of life • Clinical symptoms / cure • Adverse events • Resource use • Diagnostic test accuracy	• No comments	• No comments	• No comments
Guideline committee composition • Consultant in infectious diseases (adult) • Consultant in infectious disease (paediatric) • General practitioner x 2 • Adult general physician (or general/rheumatology) • General paediatrician • Adult neurologist	The group suggested the following should be considered for the GC composition: • Bioethical considerations specialist • Immunologist as co-opted • Dermatologist as co-opted • One GP who has experience of Lyme disease and One GP who hasn't	• May not need psychologist; could be changed to neuro-psychiatrist (could be co-opted expert). • Dermatology nurse • GPs and general physicians are trained in endocrinology, gastroenterology etc., so don't need additional specialists. • Immunology expertise is needed if it is not covered in the current group. • TB infection nurse? Primary/community nurse advert	• Adult General Physicians – do they exist? • No paediatric neurologist • No psychiatrist/psychologist • GP – one from rural area one from non-rural • Immunologist?

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• Paediatric neurologist • Microbiologist • Rheumatologist • Psychiatrist/psychologist • Practice nurse / primary care nurse or pharmacist with experience of identifying infection in the community • Lay member x 2 <u>For consideration as expert advisers (TBC)</u> • Chronic fatigue syndrome expert • Alternative medicine practitioner • Cardiologist		may cover.	
Other issues	None	Suggestion to change the title from Lyme disease to Lyme borreliosis (in line with other European guidelines).	None