

PROPOSALS FOR BUILDING PUBLIC MESSAGING ON LYME DISEASE

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This summary document provides contexts to the challenges and informational needs in improving Lyme disease awareness and prevention. It includes some ideas and suggestions that may be considered.

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BACKGROUND ON LYME DISEASE

What is Lyme disease?

Lyme disease is a tick-borne bacterial infection. It is the most common tick-borne infection in the northern hemisphere¹, with different clinical pictures described in Europe from the late 1800's where it was known by multiple different names. An outbreak of what was initially thought to be paediatric arthritis in Old Lyme, Connecticut in the 1970's, led to investigations where the causative bacteria was eventually discovered, and the name of 'Lyme' was bestowed upon this old infection.

Lyme disease is treated with antibiotics – the type and duration is dependent on the severity of disease. NICE guidance² is available to guide initial treatment of both early disease, and early disseminated disease (where it can affect the heart, the nervous system and/or the joints). It has the potential to cause long term multi-system illness if diagnosis is delayed or treatment inadequate. Deaths have been recorded – some were only discovered on further investigation in post-mortems prior to organ donation³.

Following an infected tick bite, symptoms may appear within days, weeks, or sometimes be delayed by months (e.g. presenting with disseminated disease, e.g. Lyme carditis). There is no proven minimum time of tick attachment for Lyme disease transmission to occur.

What is a tick?

A tick is a tiny blood sucking arthropod. Their size varies according to the stage of their life cycle, as demonstrated in the photo below:



Tick-Tactics: on ticks and tick-borne pathogens, twitter @heinsprong

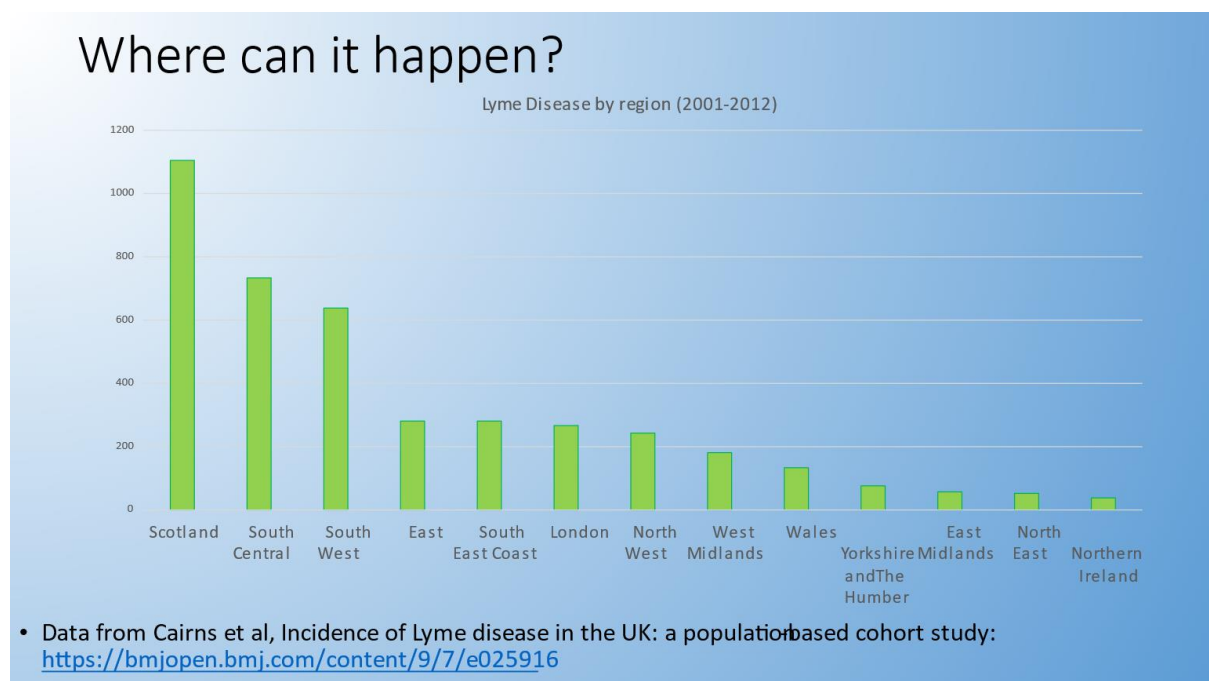
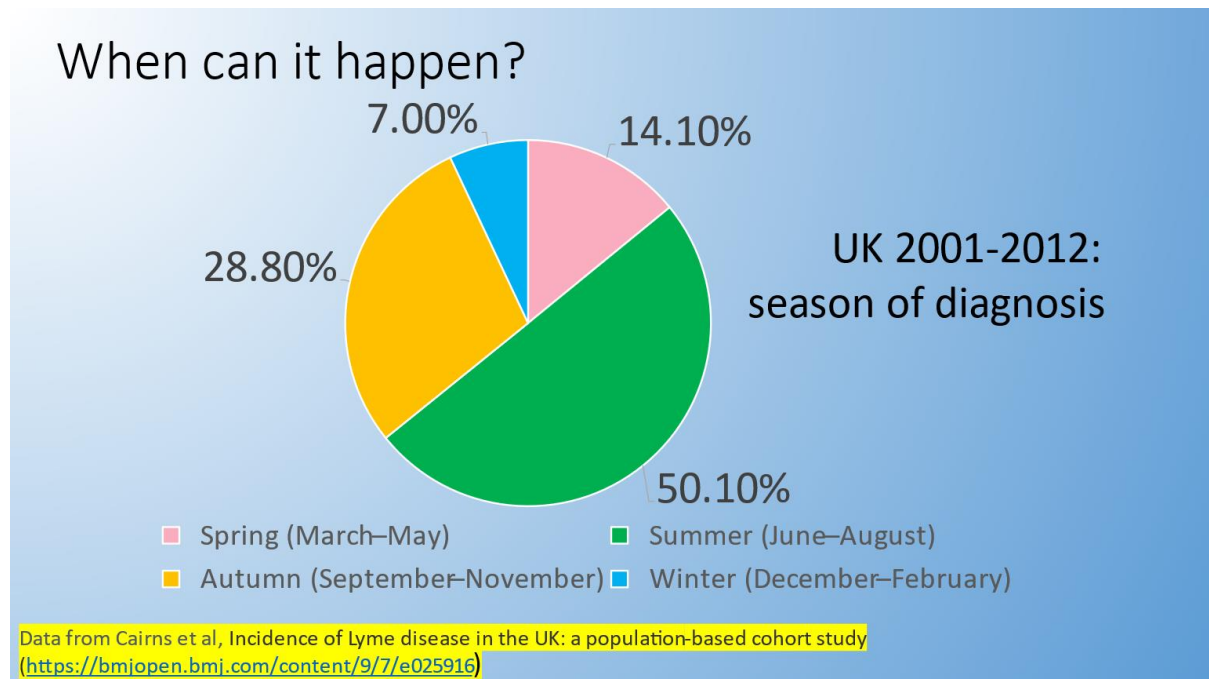
Tick bites are usually painless, so may not be noticed by those who have been bitten.

They feast on a variety of hosts, from the small (birds, mice and other small mammals), to the large (pets, farm animals, wild animals, humans).

When and where can infection happen

Lyme disease infection can happen throughout the year. A recent UK based study of GP records indicated over 90% of cases are identified in spring, summer and autumn⁴.

It is not limited to rural areas. Infections can occur in urban and peri-urban areas. There is higher risk of transmission where there is a high proportion of infected ticks coupled with greater likelihood of human contact⁵.



Removing a tick safely

A tick must be removed in such a way to avoid it regurgitating its gut contents into the skin (may increase the risk of infection), or leaving the mouthparts in the skin.

Examples of information on safe tick removal:

https://www.cdc.gov/ticks/removing_a_tick.html

<https://www.lymediseaseaction.org.uk/about-ticks/tick-removal/>

<https://lymediseaseuk.com/tick-removal/>

<http://www.ticks.ie/remove.html>

<http://www.ticks.scot/remove.html>

Videos of safe tick removal:

University of Maine: <https://www.youtube.com/watch?v=XZ14TP7FSQk>

RCGP – tick twister video: <https://www.youtube.com/watch?v=j36Cw7utM7E>

University of Manitoba: <https://www.youtube.com/watch?v=27McsguL2Og>

Insider, tick twister video: https://www.youtube.com/watch?v=k0ow_yWLZoM

POSTER CONSIDERATIONS

Areas of informational need

- For the public:
 - Safe use of the outdoors – tick bite prevention.
 - Early identification of symptoms of Lyme disease, to prompt seeking of medical attention.
- For healthcare professionals:
 - Aids to support early identification of Lyme disease

Any information campaign to pharmacies aimed at the public ideally should include a brief to the pharmacists on how to identify possible Lyme disease and when to refer to doctors (e.g. risk factors, the different forms of erythema migrans etc).

This can be in the form of accompanying leaflets for the pharmacists, or an email/letter with summarised information. There is good information available on the RCGP Lyme disease toolkit, and leaflets produced by the Lyme disease charities.

Breakdown of specific knowledge needs for the general public

- Ticks
 - What is a tick?
 - Why should I know about ticks? What does it matter to me?
 - How to identify you have been bitten? What should I look for?
 - How to remove it safely?
 - How to avoid bites? How to protect myself while enjoying the outdoors?
 - When to seek help post tick bite?
- Lyme disease infection
 - What are the signs and symptoms of Lyme disease?
 - How and when to seek help/medical attention?

Challenges to the information campaign

- **Lack of assumed knowledge**
 - Amongst general public
 - Many public health campaigns build on assumed knowledge
 - E.g. a persistent cough is worth seeing a doctor – this builds on public knowledge that lung cancer is a possibility (THE DISEASE) and that smoking or industrial exposure is a risk factor (RISK FACTOR). This knowledge has been built by multiple information campaigns over previous years/decades.
 - The current challenges in Lyme disease awareness is lack of widespread basic knowledge of both **the disease** (symptoms of both early and disseminated disease, erythema migrans, etc) and **the risk factors** (ticks, tick bites, outdoor exposure history, lack of bite prevention measures, etc).
 - Amongst healthcare professionals
 - Lack of knowledge on presenting symptoms (including erythema migrans identification), risk factors (including that tick bites may not be remembered, and that history of outdoor exposure needs to be specifically sought), and availability of NICE treatment guidelines.
- **Stigma**
 - Historical underestimation of disease prevalence and severity amongst both the general public and healthcare professionals.
- **Theoretical business concerns that messaging may impact on attraction to the outdoors**
 - This has been managed successfully in other similar contexts:
 - Sun and skin cancer risk: many people enjoy the sun and travelling to sunnier climes, while having good awareness of sun-safe behaviour and the risks and identification of skin cancer. There has been a differentiation between public health messaging on enjoying the sun safely – which has remained light-hearted while providing clear messaging (e.g. Australian Slip, Slop, Slap campaign), and separate messaging on identifying possible skin cancers and when to seek medical attention.
 - Tropical travel and diseases: people happily travel to destinations known to have risk of tropical diseases (e.g. malaria), but are knowledgeable on how to take sensible precautions to reduce the risk of infection, and to know when to seek medical attention.
- **A medically complex infection...**
 - Difficult to identify
 - needs informed and high clinical suspicion based on patient history, risk factors and clinical signs
 - The test is not absolute
 - No direct test of infection exists.
 - Test is dependent on immune response to the infection (antibody test). A positive response can be delayed by weeks to months.

- This is complicated by evidence that the infection evades the immune system – which means that those who are sickest, may have a very delayed immune response, so not test positive^{6,7}.
 - Diagnosis is based on patient history, risk factors, symptoms and clinical signs (e.g. erythema migrans only happens in Lyme disease, but has multiple different appearances, can vary with skin colour, and is absent in approximately a third of patients)^{8, 9, 10, 11}.
 - Tick bites may not be remembered
 - They are tiny – so can be easily missed.
 - They can be painless, so may not be felt at all.

- **Myths – some examples:**

MYTH	REALITY
<i>'You can only get Lyme disease if you remember a bite'</i>	Ticks are tiny, and bites can be painless, so bites may not be noticed, or remembered.
<i>'Lyme disease is in America, not here in the UK'</i>	Lyme disease is the most common tick-borne infection in the northern hemisphere. Historical records suggest it may originate in Europe.
<i>'If it's not a Bull's eye rash, it's not Lyme disease'</i>	Erythema migrans (the rash unique to Lyme disease) has many different appearances – the Bull's eye rash may only account for around 20-30% of erythema migrans rashes.
<i>'A tick must be attached for hours/days to catch Lyme disease'</i>	There is no proven minimum attachment time for transmission of infection
<i>'You can remove a tick by squeezing it/pulling it/putting butter on it/putting Vaseline on it/sticking a cigarette on it,' etc</i>	Unsafe methods of removal can lead to the tick regurgitating its gut contents into the skin and increasing the risk of transmission.

Brainstorming of possible frameworks

THEME	SPECIFICS
Prevention	<ul style="list-style-type: none"> • Shield, Scan, Scrub, and Scan again
Combined approach	<ul style="list-style-type: none"> • Reality /Realise - Why should this matter to me? • Repel - I want to continue to enjoy the outdoors how can I protect myself? • Recognise - What should I look for? • Remove - correct tick removal • Refer - yourself for professional help. What do I do if I find anything or experience the signs and symptoms of Lyme disease?
Combined approach	<ul style="list-style-type: none"> • Recognise - The risk of ticks and infections (incorporate info from your points realise / repel / recognise below) • Remove - Safely Remove • Refer – when to seek medical attention
Identification of Lyme disease	<p>Will need to allude to risk factors and symptoms, i.e.:</p> <ul style="list-style-type: none"> • Outdoor exposure • May not have memory of tick bite – but if so, helps build a clinical picture • Flu-like symptoms that may be out of season, or lasting longer than anticipated • Erythema migrans rash (including variety) • Other symptoms (e.g. heart, joint or neurological)

Consider addition of QR codes in posters linking to further information or patient leaflets.

While both tick bite prevention and early disease identification are important factors, there is an urgency to educate the public on early identification of Lyme disease to facilitate prompt treatment.

Love the outdoors?

Enjoy it safely

Be Tick Savvy

Recognise Lyme disease

Get Clear Information
Visit the RCGP Lyme disease toolkit

Be Tick Savvy...

Shield!



- Know how to safely remove ticks
- Wear long sleeves, trousers and light coloured clothing
- Tuck trousers into socks
- Use insect repellent
- Stick to the path – avoid long grass/bracken!

Scan!



- Check for ticks while outdoors and again when indoors
- Check all areas including hair and areas that were covered
- Remove ticks safely

Scrub!



- Wash yourself
- Wash your clothes (min. 55C)

...and SCAN AGAIN

- For ticks that may have been missed
- For unusual rashes in the following weeks!



For more info visit [Lyme Resource Centre](#), [Lyme Disease UK](#) or [Lyme Disease Action](#)

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Be Tick Savvy...



Shield!



- Know how to safely remove ticks
- Wear long sleeves, long trousers and light coloured clothing
- Tuck trousers into socks
- Use insect repellent
- Stick to the path – avoid long grass/bracken!



Scan!



- Check for ticks while outdoors and again when indoors
- Check all areas including hair and areas that were covered
- Remove ticks safely



Scrub!



- Wash yourself
- Wash your clothes (55C)

...and SCAN AGAIN

- For ticks that may have been missed
- For unusual rashes in the following weeks!



Visit Lyme Resource Centre for more info

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Nature is fun! Explore it safely. Be Tick Smart!



Shield!



- Cover up!
- Keep it light and bright!
- Tuck it in!
- Bug spray!
- Stick to the path!



Scan!



- Tick check!
- Ask a trusted adult to help!



Scrub!



- Wash yourself!
- Wash your clothes!

...and SCAN AGAIN

- Tick check!
- New rashes?
- Speak to your parent/guardian!



Visit Lyme Resource Centre for more info

TICK WATCH!

Shield! Scan! Scrub!

Nature is full of adventures!
Explore it safely. Be Tick Smart!



SHIELD

- Cover up!
- Keep it light and bright!
- Tuck it in!
- Anti-Bug spray!
- Stick to the path!



SCAN

- Tick check!
- Ask a trusted adult to help!



SCRUB

- Wash yourself!
- Wash your clothes!



...and SCAN AGAIN

- Tick check!
- New rashes?
- Speak to your parent/guardian!



Visit Lyme Resource Centre for more info

Where there is greenery...
there could be ticks.



Be Tick Savvy

**Get Clear Information
Visit Lyme Resource Centre Online**

Lyme disease?



Get Clear Information

What is it?
How to prevent it. How to recognise it.
What to do next.

Visit Lyme Resource Centre Online

Further reading

Tick-borne infections at risk groups:

https://www.lymeresourcecentre.com/system/files/news/2021/TickBorneInfectionAtRiskGroupsOct2021_0.pdf

Source of further information for the general public and healthcare professionals:

RCGP Lyme disease toolkit - <https://elearning.rcgp.org.uk/mod/book/view.php?id=12535>

Patient support charities (all have patient leaflets):

Lyme disease action - <https://www.lymediseaseaction.org.uk/>

Lyme disease UK - <https://lymediseaseuk.com/>

Lyme resource centre - <https://www.lymeresourcecentre.com/>

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- 8 - <https://www.bayarealyme.org/get-help/skin-rashes/>,
- 9 - <https://www.nice.org.uk/guidance/ng95/resources/lyme-disease-rash-images-pdf-4792273597>
- 10- https://www.cdc.gov/lyme/signs_symptoms/rashes.html
- 11 - <https://www.cureus.com/articles/24863-lyme-disease-with-erythema-migrans-and-seventh-nerve-palsy-in-an-african-american-man>
- 12 - All poster drafts made by Dr Z Husain March 2022.