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# Time is ticking:

A needs assessment for Lyme disease health promotion

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### **Summary**

#### Introduction

- Tick submissions to Brant County Health Unit have increased over recent years, possibly
  indicating a tick population being established. One type of tick— the blacklegged tick—
  can spread Lyme disease (LD), a bacterial infection caused by Borrelia burgdorferi.
- As part of a needs assessment around LD health promotion for the Health Unit, a literature review was conducted.

#### **Methods**

 The literature search focused on how LD information can best be communicated to the general public, priority groups, and physicians, and what types of health promotion activities are delivered to these groups.

#### **Results**

- Few resources are available on LD health promotion. Most are single studies that
  measure the knowledge, practices, or perceptions of LD in the general public or among
  healthcare practitioners.
- Studies suggest a lack of general LD knowledge among physicians.
- Levels of LD knowledge in the general public vary, but the amount of knowledge does not predict if a person uses tick-prevention behaviours. Behaviours are more likely to be performed if their benefits are seen as outweighing their inconvenience.
- The importance of local context was a key theme in the literature. Different settings influence the public's perception of LD risk and their likelihood of performing prevention behaviours.

#### **Discussion & Conclusion**

- A community's particular beliefs around risk levels and attitudes toward prevention behaviours will determine the effectiveness of LD promotion efforts. Determining the local epidemiological setting and local contexts are necessary in order to effectively tailor public health campaigns.
- Chronic Lyme disease is a current controversy that should be noted in any promotional campaigns. Advocacy groups disagree with established diagnosis and treatment guidelines, and may promote unscientific information. It is important to point to scientific and authoritative sources of information.
- The body of evidence on LD health promotion is small and not necessarily generalizable.
   Additional work will need to be done at the local level, and should incorporate greater consideration of behavioural change theories.

#### Introduction

Lyme disease is the most commonly reported vector-borne disease in North America, and has been endemic in Canada since the 1980s. The range of the tick carrying the Lyme disease (LD) bacterium is expanding (1). In the future it is likely most Canadians will live in regions where the tick is present and LD is endemic.

Many public health units currently accept ticks collected by the public and submit them to public health laboratories that identify the tick species. If the species is the type that carries LD, ticks are sent to the National Microbiology Laboratory to be tested for the LD bacterium. Public health inspectors gather information from submitters and follow up with them once results are received from the laboratory.

Tick submissions to the Brant County Health Unit have increased over recent years.

Changing environmental conditions and the expanding range of the tick may mean a tick population is being established in the Health Unit's jurisdiction. This prompted a needs assessment around developing LD health promotion. The needs assessment was completed as a student practicum placement project; one component of this needs assessment was a literature review. The results of this review are described herein.

#### Background

#### What is Lyme disease?

#### Signs, symptoms, stages

Lyme disease is a tick-borne bacterial infection caused by the spirochete *Borrelia* burgdorferi, which is transmitted to humans through the bite of an infected tick. LD symptoms can vary. A typical presentation involves an *erythema migrans* rash (in about 70% of cases). The

rash's well-known "bull's eye" presentation only occurs in approximately 20% of cases. Other common symptoms include headaches, fever, chills, and fatigue, though different symptoms can occur at different stages of the disease (2). The non-specificity of symptoms can make diagnosis difficult.

#### Diagnosis and treatment

The diagnosis of LD is primarily clinical, based on signs and symptoms supported by a history of possible tick exposure. Ontario's *Infectious Diseases Protocol* for LD (3) does not recommend testing ticks to guide the management of patients; tick identification and testing is primarily used for surveillance purposes only.

An additional diagnostic tool uses a two-tiered serological method to detect antibodies in a patient's blood (4). However, laboratory testing should only be used to supplement clinical findings, not as a basis for diagnosing early stage LD. Patients with clear symptoms of early LD should be treated without laboratory confirmation, because false negative findings are possible during early stages. The recommended treatment is antibiotics (doxycycline). Controversies exist around providing long-term antibiotic treatment for "chronic" LD (5, 6).

#### Ticks – vector and reservoir

B. burgdorferi is transmitted via the bite of an infected tick. The primary vector for B. burgdorferi in eastern North America is Ixodes scapularis – the blacklegged tick, also known as the deer tick.

Ticks become infected by feeding on hosts for *B. burgdorferi* (deer, birds, and rodents).

Blacklegged ticks have a two-year life cycle of larva, nymph, and adult stages (7), each which feeds once and during different seasons. Nymphs feed in the spring and summer, which is when

humans are most at risk of contracting LD. Nymphs are most responsible for human infections because their small size makes them hard to see. Adult ticks are active in the spring and fall, and because they have had two chances to feed they are more likely to test positive for *B. burgdorferi*. Bacteria live in the gut of the tick and migrate into the salivary glands when feeding begins; this takes approximately 24 hours, meaning there is very little risk of bacteria being transmitted if an infected tick is attached for less than 24 hours.

#### Surveillance

#### Human surveillance

LD has been a notifiable disease in Ontario since 1988 and a nationally notifiable disease since 2010 (8). In Ontario, LD is both a reportable and communicable disease under the Ontario *Health Protection and Promotion Act*. Physicians and nurse practitioners are required to report suspected, probable and confirmed LD cases to the local Medical Officer of Health, who must then report those cases to the Ministry of Health and Long-Term Care (MOHLTC). Health units conduct human surveillance by collecting epidemiological data from cases of suspected or diagnosed LD.

#### Tick surveillance

Tick surveillance determines how established tick populations are within an area. This then informs the risk of LD infection for humans. There are two main types of surveillance:

- Active surveillance collecting ticks from their natural habitat using methods such as drag sampling and small animal capture.
- Passive surveillance examining ticks submitted to a health unit by the public. (9)

In Ontario, blacklegged ticks are most commonly found along the north shores of Lake Erie, Lake Ontario, and the St. Lawrence River (8, 10). The risk of acquiring LD is greatest in endemic areas because the probability of being bitten by an infected tick is greater. However, ticks also feed on migratory birds that can then transport ticks throughout the country. Thus it is possible for people to be infected with LD almost anywhere in Canada.

#### **Prevention and protection**

Recommendations to prevent LD focus on reducing one's exposure to infected ticks. These methods are largely reliant on individuals. They include using chemical repellents, wearing protective clothing, avoiding risk areas, modifying landscape, checking for ticks after being outdoors, and removing discovered ticks within 24 hours of attachment (11, 12). These methods are simple, but are limited by user adherence. Other methods include coordinated local efforts that aim to reduce tick densities in places where people are likely to be exposed; these activities include pesticide spraying, reservoir-targeted vaccines, deer culls, and treatment of deer and rodents with acaricides that kill ticks on animal hosts.

A human LD vaccine (LYMErix<sup>™</sup>) was the only intervention ever shown to have reduced human illness in large community trials, but it is no longer available. The most effective means of preventing LD will likely require a combination of personal protective behaviours and coordinated local actions (11). Education and information on prevention behaviours can be provided through LD health promotion efforts.

#### **Methods**

A literature search on LD health promotion was conducted to determine:

- how disease information can best be communicated to the general public, priority groups, and physicians;
- and what types of health promotion activities about Lyme disease are delivered to these groups.

The specific search strategy, including keywords used and databases searched, can be found in Appendix A. A summary of the search process and results is presented in Appendix B. A total of 61 sources were found to be relevant and were entered into an annotated bibliography. A shortened version of the bibliography is presented in Appendix C.

#### Results

The relevant sources were mostly single studies from academic journals. Few results specifically dealt with LD health promotion; most of the literature was clinically-focused. The majority of relevant sources (20 results) involved measuring knowledge, practices, or perception of LD in the general public; another common theme was measuring LD knowledge and practices of healthcare providers (8 results). Little was available on LD programs/campaigns, or educating patients or the public about LD, although some non-academic resources were found.

#### Healthcare provider knowledge, practices, perceptions

Most articles that dealt with healthcare providers tried to characterize the knowledge practitioners had regarding LD and how they managed LD patients. Results varied, but there appeared to be a lack of general LD knowledge among physicians, including a false belief that

laboratory testing is necessary before treating tick bites (13, 14). One worrisome finding was that physicians will often treat patients with antibiotics despite not believing it was indicated (14, 15).

#### Public knowledge, practices, perceptions

Numerous studies measured the level of LD knowledge and the extent of performing tick prevention behaviours among the general public. Results showed variable rates of prevention behaviours, but in general checking for ticks after being outdoors was most commonly performed, while repellent use was least common(16,17). Performing behaviours to reduce LD risk tended to be low even when knowledge of LD was adequate. People were more likely to undertake prevention behaviours when they had personal experience with the disease (18). It was important that the benefits of a behaviour were seen to outweigh its inconvenience (19). Studies emphasized the importance of social and contextual factors, where different epidemiological settings shaped the public's perception of ticks being a risk (20-22).

#### Patient/public education

There are few articles available on how best to communicate LD information to patients or the public. Those that were found emphasized the need to customize messages for specific population segments (23, 24). Most results within this theme were about LD information on the internet (25-27), and highlighted that there is much conflicting and inaccurate information available online that is easily accessible to patients.

#### Health promotion campaigns, educational interventions

Few studies have examined campaigns or interventions around LD prevention behaviours, and even fewer were randomized control trials (28, 29). One systematic review

assessed the impact of educational interventions around preventing tick-borne diseases (30). The authors concluded that while participants' knowledge and behaviours were amenable to change, the lasting impact of the interventions was unknown. The interventions used (e.g., an entertainment troupe, mailing campaigns) were labour-intensive, costly, and tended to involve multiple components. Being able to identify which aspects were most effective would allow for a greater focus in planning behavioural interventions and educational campaigns. There is a need for more methodologically-robust and theory-driven research on this topic.

#### **Prevention methods**

These articles focused on tick prevention methods that may be useful to promote to the public and to incorporate when developing LD management plans. While tick prevention advice is fairly repetitive, one result described a unique prevention program in a Pennsylvania health unit that provided risk assessment, education, and medical referrals (31).

#### Resources

Some journal articles included factsheets to print and distribute to patients. Most articles recommended visiting the websites of the Centers for Disease Control and Prevention (CDC), Infectious Disease Society of America, European Centre for Disease Control and Prevention, and Public Health Agency of Canada for further information. These sites are the authorities on LD, and contain resources for both the public and health practitioners. Specific LD programs were mentioned, such as the BLAST! Lyme disease prevention program and the Tick Encounter resource centre, although these are tailored to specific (and American) contexts.

#### **Discussion**

#### Importance of local context in LD promotion

Literature examining the public's knowledge, practices, and perceptions of LD has thus far focused on measuring knowledge as the key outcome, rather than behaviour. Behaviours to prevent tick bites are often grouped together, making it difficult to analyze the role of different variables in motivating specific behaviours. There has also been little consideration of health psychology or behavioural change theories (30). The Health Belief Model (HBM) is one such theory, dealing with individual perceptions about one's susceptibility to a disease threat, its severity, the benefits and barriers to adopting a behaviour, and one's self-efficacy in performing that behaviour. Components of this theory were present in a number of studies, providing some insights into what predictors of tick prevention behaviours might be. This included: awareness and knowledge about ticks (22, 32), self-efficacy for performing behaviours (19, 33), and the perceived likelihood of contracting LD (32).

These perceptions are shaped by the social and contextual factors in local epidemiological settings. For instance, in LD-emerging areas, beliefs about risk are influenced by generally available information; in endemic areas, risk perception is influenced more by personal experience with the disease. This shows the importance of involving the community when designing public health campaigns and interventions, in order to determine the specific context in an area and tailor approaches to it.

#### **Chronic Lyme controversy**

The sources excluded from the literature review results were also informative. A large number (58) were excluded due to being commentaries, letters to the editor, or author replies – the majority of which revolved around the controversy of "chronic" Lyme disease.

Chronic LD is a poorly defined term used to describe various non-specific and subjective symptoms (such as chronic pain, fatigue, and neurocognitive issues) that are attributed to persistent *B. burgdorferi* infection (6). There is no accepted clinical definition for chronic LD and most patients with a chronic LD diagnosis have no evidence of prior LD infection. Advocacy for chronic LD has become a contentious political issue and has developed into an anti-science movement, with claims of conspiracies and corruption (5). A community of private laboratories and alternative practitioners ("Lyme literate MDs") has emerged, who provide unreliable diagnoses and unorthodox therapies that are potentially harmful (34).

A more in-depth discussion of this controversy is beyond the scope of this report.

However, the literature review revealed numerous studies where physicians would treat patients with antibiotics despite no indication of LD (14, 15), perhaps to calm worries around chronic LD. Prolonged antibiotic therapy can have adverse events and there is no evidence to suggest *B. burgdorferi* infection persists long-term (35). It is important for physicians to be aware of this issue and be able to provide patients with appropriate scientific information.

# **Strengths and limitations**

A strength of this literature review was the numerous keywords used and databases searched, without limiting results to any particular study type. Many results were assessed for relevancy, making it likely that most relevant sources would have been found. While thorough,

the review returned few results that were directly on point and dealt with LD health promotion.

Most results were single studies; only one systematic review was found. This means conclusions were drawn from lower levels of research evidence, none of which precisely matched Brant County Health Unit's particular epidemiological context (i.e., a low-risk area in Ontario).

The results of prior studies are not necessarily generalizable across different settings. The literature review retrieved studies set mostly in the United States (in both endemic and non-endemic areas) and some in Europe, but only 7 in Canada. None were set in Ontario, although some were set in LD-emergent areas in Quebec (13, 20).

The literature stresses the importance of exploring public perceptions. The existing body of research can provide a starting point for developing LD health promotion campaigns, but a gap in research and knowledge exists in the applicability of prior research to local contexts.

Additional work will need to be done at local levels in order to tailor approaches for maximum efficacy. This work should more thoroughly incorporate behavioural change theories and consider behaviour change as the outcome of interest.

#### Conclusion

This literature review on Lyme disease health promotion supplemented a needs assessment for Brant County Health Unit. Evidence suggests it is only a matter of time before ticks establish themselves in the Brant County area – the clock is ticking, but there is an opportunity to be proactive and plan for future LD health promotion. The existing body of evidence is sparse and may not be directly applicable to the Health Unit's context, but it is able to provide a starting point and offer guidance on how the Health Unit can move forward to communicate key messages on LD.

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#### References

- (1) Ogden NH, Lindsay LR, Morshed M, Sockett PN, Artsob H. The emergence of Lyme disease in Canada. CMAJ: Canadian Medical Association Journal 2009;180(12):1221-1222.
- (2) Centers for Disease Control and Prevention. Signs and Symptoms of Untreated Lyme Disease. 2015; Available at: http://www.cdc.gov/lyme/signs\_symptoms/index.html.
- (3) Ontario Ministry of Health and Long-Term Care. Infectious Diseases Protocol Appendix A: Disease-Specific Chapters. 2015.
- (4) Centers for Disease Control and Prevention. Two-step Laboratory Testing Process. 2015; Available at: http://www.cdc.gov/lyme/diagnosistesting/labtest/twostep/index.html.
- (5) Auwaerter PG, Bakken JS, Dattwyler RJ, Dumler JS, Halperin JJ, McSweegan E, et al. Antiscience and ethical concerns associated with advocacy of Lyme disease. The Lancet Infectious Diseases 2011;11:713-719.
- (6) Lantos P. Chronic Lyme Disease. Infect Dis Clin North Am 2015;29(2):325-340.
- (7) Centers for Disease Control and Prevention. Transmission. 2015; Available at: http://www.cdc.gov/lyme/transmission/index.html.
- (8) Public Health Agency of Canada. Surveillance of Lyme Disease. 2015; Available at: http://www.healthycanadians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/lyme/surveillance-eng.php.
- (9) Ontario Agency for Health Protection and Promotion (Public Health Ontario). Technical Report: Update on Lyme Disease Prevention and Control. 2012.
- (10) Ontario Agency for Health Protection and Promotion (Public Health Ontario). Lyme disease risk areas. 2015.
- (11) Ogden NH, Lindsay LR, Schofield SW. Methods to Prevent Tick Bites and Lyme Disease. Clin Lab Med 2015;35:883-899.
- (12) Wormser GP. Clinical practice. Early Lyme disease. N Engl J Med 2006;354:2794-2801.
- (13) Ferrouillet C, Milord F, Lambert L, Vibien A, Ravel A. Lyme disease: Knowledge and practices of family practitioners in southern Quebec. Canadian Journal of Infectious Diseases and Medical Microbiology 2015;26:151-156.

- (14) Henry B, Crabtree A, Roth D, Blackman D, Morshed M. Lyme disease: Knowledge, beliefs, and practices of physicians in a low-endemic area. Canadian Family Physician 2012;58:e289-e295.
- (15) Perea AE, Hinckley AF, Mead PS. Tick Bite Prophylaxis: Results From a 2012 Survey of Healthcare Providers. Zoonoses & Public Health 2015;62:388-392.
- (16) Herrington JE. Risk perceptions regarding ticks and Lyme disease: a national survey. Am J Prev Med 2004;26:135-140.
- (17) Valente SL, Wemple D, Ramos S, Cashman SB, Savageau JA. Preventive behaviors and knowledge of tick-borne illnesses: results of a survey from an endemic area. Journal of Public Health Management & Practice 2015;21:E16-23.
- (18) McKenna D, Faustini Y, Nowakowski J, Wormser GP. Factors influencing the utilization of Lyme disease-prevention behaviors in a high-risk population. J Am Acad Nurse Pract 2004;16:24-30.
- (19) Shadick NA, Daltroy LH, Phillips CB, Liang US, Liang MH. Determinants of tick-avoidance behaviors in an endemic area for Lyme disease. Am J Prev Med 1997;13:265-270.
- (20) Aenishaenslin C, Ravel A, Michel P, Gern L, Milord F, Waaub JP, et al. From Lyme disease emergence to endemicity: a cross sectional comparative study of risk perceptions in different populations. BMC Public Health 2014;14:1298.
- (21) Aenishaenslin C, Michel P, Ravel A, Gern L, Milord F, Waaub J, et al. Factors associated with preventive behaviors regarding Lyme disease in Canada and Switzerland: a comparative study. BMC Public Health 2015;15:1-10.
- (22) Beaujean DJ, Gassner F, Wong A, Steenbergen van JE, Crutzen R, Ruwaard D. Determinants and protective behaviours regarding tick bites among school children in the Netherlands: a cross-sectional study. BMC Public Health 2013;13:1148-1148.
- (23) Anderson A, Chaney E. Tick-associated diseases: symptoms, treatment and prevention. American Journal of Health Education 2009;40:183-189.
- (24) Marzano M, Moseley D, Quine CP, Barnett J. Organisational intentions and responses: presenting the risk of Lyme disease to countryside users. Journal of Environmental Planning & Management 2013;56:305-328.
- (25) Cooper JD, Feder HM Jr. Inaccurate information about Lyme disease on the internet. Pediatr Infect Dis J 2004;23(12):1105-1108.
- (26) Hartmann J. Infectious diseases on the World Wide Web. Med Ref Serv Q 2004;23:49-60.

- (27) Sood SK. Effective Retrieval of Lyme Disease Information on the Web. Clinical Infectious Diseases 2002;35(4):451-464.
- (28) Daltroy LH, Phillips C, Lew R, Wright E, Shadick NA, Liang MH. A controlled trial of a novel primary prevention program for Lyme disease and other tick-borne illnesses. Health Education & Behavior 2007;34:531-542.
- (29) Malouin R, Winch P, Leontsini E, Glass G, Simon D, Hayes EB, et al. Longitudinal evaluation of an educational intervention for preventing tick bites in an area with endemic Lyme disease in Baltimore County, Maryland. Am J Epidemiol 2003;157(11):1039-1051.
- (30) Mowbray F, Amlot R, Rubin GJ. Ticking all the boxes? A systematic review of education and communication interventions to prevent tick-borne disease. Vector Borne Zoonotic Dis 2012;12(9):817-825.
- (31) Hakim JA, Bitto A. Public education and Lyme disease prevention in Monroe County: a multi-faceted program of personal protection strategies, tick identification/risk assessment, bi-directional referrals, and vector control. Californian Journal of Health Promotion 2005;3:137-145.
- (32) Gould LH, Nelson RS, Griffith KS, Hayes EB, Piesman J, Mead PS, et al. Knowledge, attitudes, and behaviors regarding Lyme disease prevention among Connecticut residents, 1999-2004. Vector Borne & Zoonotic Diseases 2008;8:769-776.
- (33) Mowbray F, Amlot R, Rubin GJ. Predictors of protective behaviour against ticks in the UK: a mixed methods study. Ticks Tick Borne Dis 2014;5(4):392-400.
- (34) Lantos PM, Shapiro ED, Auwaerter PG, Baker PJ, Halperin JJ, McSweegan E, et al. Unorthodox Alternative Therapies Marketed to Treat Lyme Disease. Clinical Infectious Diseases 2015;60(12):1776-1782.
- (35) Macauda MM, Erickson P, Miller J, Mann P, Closter L, Krause PJ. Long-term Lyme disease antibiotic therapy beliefs among New England residents. Vector Borne & Zoonotic Diseases 2011;11:857-862.

# **Appendix A: Literature review search strategy**

Research	How is information about Lyme disease communicated to the general public, high-risk groups, and physicians?					
question:	2. What types of health promotion activities/campaigns about Lyme disease are delivered to the general public, high-risk groups, and physicians?					
Decision to be made:	How the Brant County Health Unit can best promote/communicate information on Lyme disease.					
Types of materials to identify:	reports, guidelines); grey literature from public health agencies (e.g.,					
Keywords:	<ul> <li>General population/public; physicians/healthcare providers/doctors/clinicians; priority groups/high-risk groups/at-risk groups/vulnerable populations</li> <li>Lyme (disease); (Lyme) borreliosis; Borrelia (burgdorferi)</li> <li>Health promotion, perceptions beliefs, attitudes, awareness, knowledge, education, practice, guidelines, campaign, intervention</li> </ul>					

Database searched:	Date of search:	Number of results found:
Embase	Week of Feb. 8	69
Ovid MEDLINE(R)	Week of Feb. 1	225
PsycINFO	Week of Feb. 1	23
CINAHL Plus with Full text	February 11	239
Academic Search Premier	February 11	92
SocINDEX with Full text	February 11	73
PubMed limited to publisher results	February 11	22
Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations	February 10	67
	TOTAL:	810

## **Appendix B: Literature review results**

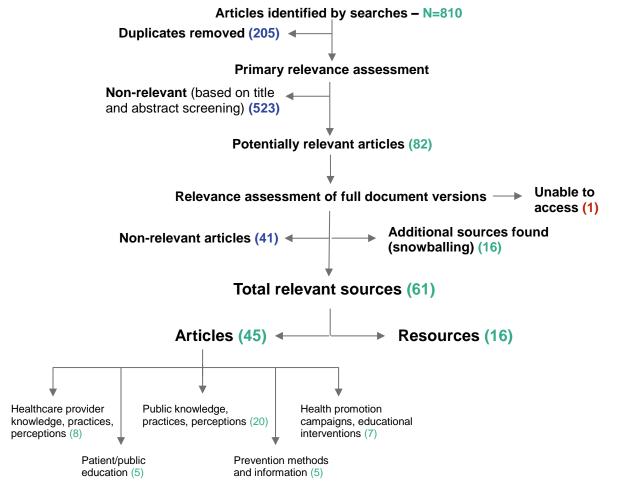
A primary relevance assessment was conducted on the literature search results. Duplicate and non-relevant results (based on scanning the title and/or abstract) were removed. The remaining results were then assessed for relevance by examining the full document. Sources were included if they:

- Focused on Lyme disease health promotion
- Involved communication with the general public, high-risk groups, or physicians
- Described Lyme disease interventions, activities, campaigns, or programs

Sources were excluded if they were:

- Focused on clinical issues (e.g. treatment, diagnosis, pathogen biology, etc.);
- Commentaries, correspondence, letters to the editor, author replies;
- Off-topic and contained no educational/promotional content.

The remaining relevant articles were added into the annotated bibliography.



Adapted from: Health-evidence.ca. (2009, November 25). Keeping Track of Search Results: A Flowchart. Retrieved February 2, 2016, http://www.healthevidence.org/practice-tools/HETools\_KeepingTrackSearchResultsFlowchart\_18.Mar.2013.ppt.

# **Appendix C: Summary Review Table of Literature Review Results**

Health-care provider knowledge, practices, perceptions – sources focusing on the actions or attitudes of professionals in the healthcare field.

Reference	Methodology	Article summary and comments
Bakken LL. Role of experience and context in learning to diagnose Lyme disease. J Contin Educ Health Prof 2002;22:131-141.	<ul> <li>Qualitative study using grounded theory methodology</li> <li>Interviews with physicians</li> <li>n=9</li> </ul>	<ul> <li>Explores experiential learning and how physicians learn to generate diagnoses, in the context of learning to diagnose LD.</li> <li>Knowing patient history/backgrounds became significant factors in framing diagnoses.</li> <li>Most physicians equated being more 'comfortable' with the diagnosis to being familiar with it, in terms of frequency of encounters. Multiple presentations of LD are important in defining the variability with which the disease can occur.</li> <li>Provides valuable 'lessons for practice' that can be incorporated into physician education materials: provide case studies with rich contextual descriptions; compare LD cases explicitly with non-LD cases and LD-like cases; present multiple and varied disease cases; provide timely feedback.</li> <li>Stresses importance in needing experience to diagnose LD; may be challenging in an emerging, nonendemic area.</li> </ul>
Brett ME, Hinckley AF, Zielinski-Gutierrez EC, Mead PS. U.S. healthcare providers' experience with Lyme and other tick-borne diseases. Ticks Tick Borne Dis 2014;5(4):404-408.	4 questions on tick- borne diseases added the 2009 DocStyles survey, a nationally representative computer survey of HCPs in the US     n=2000	<ul> <li>Characterized experiences of HCPs with tick-borne diseases.</li> <li>Over half (53.1%) of respondents had treated a patient for a tick-borne illness in the previous year, with 46.8% having encountered LD. Most providers (89%) would prescribe prophylaxis immediately, with or without ordering a blood test for LD. There is frequent prescribing of prophylaxis in low-LD-incidence areas.</li> <li>HCPs are knowledgeable about the limitations of laboratory testing for early LD, as most prescribe post-bite prophylaxis without ordering a test.</li> <li>Frequent prescribing of prophylaxis in low-LD-incidence areas implies a need for further education to reduce overtreatment.</li> </ul>
Capps PA, Pinger RR, Russell KM, Wood ML. Community health nurses' knowledge of Lyme disease: implications for surveillance and community education. J Community Health Nurs 1999;16:1-15.	<ul> <li>Questionnaire administered to public health nurses in Indiana</li> <li>n=226</li> </ul>	<ul> <li>Questions to determine general knowledge and practices about LD.</li> <li>Nurses were most knowledgeable about personal protection and least knowledgeable about symptoms, case definitions, and reporting criteria.</li> <li>Nurses with less formal education scored higher on LD questions.</li> <li>Recommendations made for disseminating LD information to nurses, such as epidemiologic newsletters with updates or in-service programs.</li> </ul>

Cartter ML, Farley TA, Ardito HA, Hadler JL. Lyme disease preventionknowledge, beliefs, and behaviors among high school students in an endemic area. Conn Med 1989;53:354-356.	<ul> <li>Survey of high school students in highly- endemic area</li> <li>n=153</li> </ul>	<ul> <li>Students surveyed about their familiarity with LD and practicing of preventive behaviours.</li> <li>90% believed tick-avoidance behaviours could prevent LD, but less than half reported practicing such behaviours. Those who perceived a specific behaviour to be preventative were 3-6 times more likely to practice it than others.</li> <li>Students who indicated they had been diagnosed with LD previously were only slightly more likely than their classmates to engage in preventive behaviours.</li> <li>The most important sources of information on LD the students identified were parents (45%), followed by doctors/nurses (24%).</li> </ul>
Crowder LA, Yedlin VA, Weinstein ER, Kortte KB, Aucott JN. Lyme disease and post-treatment Lyme disease syndrome: the neglected disease in our own backyard. Public Health 2014;128:784-791.	<ul> <li>Internet survey sent to all faculty members across all 50 accredited schools of PH in the US</li> <li>Response rate of 15% (n=1297/8962), with 50% of respondents from Lyme-endemic states</li> </ul>	<ul> <li>Assessed opinions about LD and post-treatment Lyme disease syndrome (PTLDS) among public health school faculty members.</li> <li>Less than 3% considered themselves experts on LD, fewer than 2% on PTLDS. ~66% reported no professional experience with LD, but personal experience with LD was common (6% with personal diagnosis, 34% with family/friend, and 68% knowing somebody diagnosed).</li> <li>Most were uncertain about its aetiology, felt incidence of LD would be increasing, and more education is needed.</li> <li>One of few pieces of literature related to PH personnel. Indicates respondents were not up to date on the controversy re: "chronic Lyme". PH officials may be less involved in this part of the debate (i.e. antibiotic use, treatment), but should still be aware.</li> </ul>
Eppes SC, Klein JD, Caputo GM, Rose CD. Physician beliefs, attitudes, and approaches toward Lyme disease in an endemic area. Clin Pediatr 1994;33:130-134.	<ul> <li>Questionnaires sent to practitioners in 3 states</li> <li>n=124</li> </ul>	<ul> <li>Assessed beliefs and practices of HCPs in a Lyme-endemic area.</li> <li>Considerable variability in approaches to LD, suggesting need for further trials, research, and physician education.</li> <li>Most physicians treated early LD manifestations in accordance with accepted recommendations. A striking finding was that the majority would consider using IV antibiotics in the absence of a firm diagnosis; this may lead to unnecessary treatment of patients who do not have LD, potentially due to patient pressure to diagnose LD without objective evidence.</li> </ul>
Ferrouillet C, Milord F, Lambert L, Vibien A, Ravel A. Lyme disease: Knowledge and practices of family practitioners in southern Quebec. Canadian Journal of Infectious Diseases and Medical Microbiology 2015;26:151-156.	Questionnaire on experiences, knowledge of LD signs and symptoms, familiarity with diagnosis and treatment guidelines     n=201	<ul> <li>LD clinical experiences of family practitioners (FPs) in two areas in QB (one with infected ticks, one without) are described.</li> <li>Those in the infected region had more experience, knowledge, and management of symptoms.</li> <li>Results demonstrated the tendency for physicians to inappropriately order serology tests for tick bites and use tick analysis for diagnosis.</li> <li>FPs demonstrated a lack of general knowledge, rather than inaccurate knowledge. Findings support the need for PH authorities to provide more information to practitioners.</li> </ul>

Henry B, Crabtree A, Roth D, Blackman D, Morshed M. Lyme disease: knowledge, beliefs, and practices of physicians in a low- endemic area. Canadian Family Physician 2012;58:e289-95.	<ul> <li>Questionnaire to assess awareness, knowledge of LD administered to physicians in a low- prevalence area (BC)</li> <li>Response rate of 32% (n=1673/5199)</li> </ul>	<ul> <li>Average knowledge score for FPs was 72.5%, 75% for other specialists. Most respondents underestimated the occurrence of erythema migrans, and only about ¼ knew EM was diagnostic for LD. ~30% had treated a patient for LD despite not believing the patient actually had the disease. Only 62% knew LD was a reportable disease.</li> <li>Testing in the absence of clinical findings may result in false positives, leading to unnecessary treatment. Testing and treating asymptomatic patients also occurred, potentially related to "Lyme anxiety" and pressure from advocacy groups.</li> </ul>
Perea AE, Hinckley AF, Mead PS. Tick Bite Prophylaxis: Results From a 2012 Survey of Healthcare Providers. Zoonoses & Public Health 2015;62:388-392.	4 questions on LD included in the 2012 DocStyles survey, a self-administered computer questionnaire of 2205 US HCPs     n=1485	<ul> <li>HCPs were surveyed to examine how often and for what reasons they prescribed post-bite prophylaxis (PBP) for ticks.</li> <li>56.4% of respondents reported prescribing PBP at least once in the past year; more common in high LD incidence areas (73.9%) than low LD incidence areas (48.2%). The most common reason provided was "to prevent Lyme disease" (76.9%), followed by "patients requested it" (40.4%).</li> <li>Of those who provided PBP, 45.2% did so even though they felt it was not indicated. Overall, HCPs are prescribing PBP frequently in areas were LD is rare and for other tick-borne diseases for which PBP has not been shown to be effective.</li> </ul>

### Public knowledge, practices, perceptions – sources focusing on attitudes and actions of *non*-healthcare professionals.

Reference		Methodology		Article summary
Aenishaenslin C, Michel P, Ravel A, Gern L, Waaub JP, Milord F, et al. Acceptability of tick control interventions to prevent Lyme disease in Switzerland and Canada: a mixed-method study. BMC Public Health 2016;16:12.	•	Mixed-method approach Web survey and focus groups n=814	•	Acceptability of tick control strategies compared in 2 regions – one endemic (Switzerland) and one emerging (Quebec).  High acceptability of tick interventions was correlated with high perceived efficacy. Low acceptability was explained by environmental impacts, high costs, danger of individual disempowerment, and perceptions of disproportionate actions related to the level of LD risk.  Results highlight the need to consider public perceptions, which will affect the acceptability of public interventions.  Interesting perception that if PH authorities enacted interventions, individuals would feel less responsibility to adopt their own preventative behaviours.
Aenishaenslin C, Ravel A, Michel P, Gern L, Milord F, Waaub JP, et al. From Lyme disease emergence to endemicity: a cross sectional comparative study of risk perceptions in different populations. BMC Public Health 2014;14:1298.	•	Data collected via web surveys (n=814) Questionnaire administered to experts (n=16)	•	Risk perceptions of LD among general public and experts in two regions (endemic – Switzerland, and emerging – Quebec) are compared.  In QB, only 15% of respondents felt they had a good level of knowledge; 24% perceived themselves at high or very high risk of contracting LD; 73% felt personal protection was simple to enact.  QB residents rated their personal risk as lower than the risk for residents in their region – demonstrating 'unrealistic optimism'.  Results suggest different epidemiological settings result in different risk perceptions.

Aenishaenslin C, Michel P, Ravel A, Gern L, Milord F, Waaub J, et al. Factors associated with preventive behaviors regarding Lyme disease in Canada and Switzerland: a comparative study. BMC Public Health 2015;15:1-10.	<ul> <li>Web-based surveys in Quebec, Switzerland</li> <li>n=814</li> </ul>	<ul> <li>Perceived efficacy of preventative measures among QB population showed that tick checks (58%), risk area avoidance (76%) and protective clothing (83%) were considered most effective. Age range of 35-54 was negatively associated with using protective clothing.</li> <li>Highest level of adoption of prevention measures in QB was 50% using protective clothing among those who know of LD before taking the survey – perhaps indicative of a lack of knowledge of disease transmission.</li> <li>Results stress the importance for PH authorities to understand and monitor social and contextual factors when implementing prevention campaigns.</li> </ul>
Aucott JN, Crowder LA, Yedlin V, Kortte KB. Bull's-Eye and Non- target Skin Lesions of Lyme Disease: An Internet Survey of Identification of Erythema Migrans. Dermatology Research & Practice 2012;2012:1-6.	<ul> <li>Survey of visitors to LD website</li> <li>n=3,104</li> </ul>	<ul> <li>Assessed ability of the public to distinguish erythema migrans (EM) from non-LD rashes after visiting a LD educational website.</li> <li>Classic (EM) rash associated with LD is found in ~80% of patients, but can have a range of appearances different from the typical 'bull's-eye'.</li> <li>~72% were able to correctly identify the classic EM, while only ~20% could identify the non-classic EMs. Indicates a need to educate the public in order to improve early recognition of LD.</li> </ul>
Beaujean D, van Velsen L, van Gemert-Pijnen JE, Maat A, van Steenbergen JE, Crutzen R. Using risk group profiles as a lightweight qualitative approach for intervention development: an example of prevention of tick bites and Lyme disease. JMIR Research Protocols 2013;2:e45.	<ul> <li>In-depth semi-structured interviews</li> <li>Participants from health services travel health clinics (in a high-endemic area and a low-endemic area) and convenience sampling</li> <li>n=25</li> </ul>	<ul> <li>Groups at high risk of tick bites or developing LD were identified from general Dutch population to describe knowledge and perceptions around LD.</li> <li>Risk groups identified included outdoor people who do and do not check for ticks, and parents who do and do not check their children.</li> <li>Checking for bites was the more easily adopted measure over preventing tick bites, suggesting this method should be emphasized in public health efforts. Willingness to adopt measures such as wearing protective clothing was low.</li> <li>Differences among the risk groups suggest organizations should shift focus from communicating expert-driven guidelines (promoting all precautions) to communicating targeted approaches (that are more likely to fit with the perceptions of risk groups).</li> </ul>
Beaujean DJ, Bults M, van Steenbergen JE, Voeten HA. Study on public perceptions and protective behaviors regarding Lyme disease among the general public in the Netherlands: implications for prevention programs. BMC Public Health 2013;13:225.	<ul> <li>Online questionnaire</li> <li>Representative sample of Dutch general public</li> <li>n=362/550</li> </ul>	<ul> <li>Examined knowledge, risk perception, and behavioural responses to tick bites.</li> <li>Main predictors of prevention behaviours were knowledge, level of concern, and perceived efficacy. Findings suggest prevention programs should aim to influence these factors in people, such as by strengthening motivators (e.g. knowledge, concern about LD) and removing barriers (e.g. not knowing how to recognize ticks).</li> <li>Main motivators mentioned were: perceiving LD could be severe, that prevention measures are effective, personal responsibility regarding one's health, and perceiving a high chance of tick bites.</li> <li>Barriers were: being too warm to wear protective clothing, low risk of tick bites, and feeling protective clothing was an overdone message.</li> </ul>

Butler AD, Sedghi T, Petrini JR, Ahmadi R. Tick-borne disease preventive practices and perceptions in an endemic area. Ticks Tick Borne Dis 2016;7(2):331-337.	<ul> <li>Questionnaire mail out through point-of-contact convenience sample in southern Connecticut</li> <li>n=275</li> </ul>	<ul> <li>Examined knowledge about tick-borne diseases and prevention practices in Lyme-endemic area.</li> <li>Assessed general knowledge about diseases, performance of 4 prevention methods (wearing protective clothing, applying repellent, performing a "tick check", and bathing/showering within 2 hours of being outdoors), and perceived effectiveness and burdensomeness of those behaviors.</li> <li>Performance of preventive behaviours was variable, from tick checks being the most common (68%) to using repellent being the lowest (38%). Risk of contracting LD if bitten was overestimated, and underestimating attachment time needed for pathogen transmission.</li> <li>Factors other than perceived effectiveness contribute to the performance of a behaviour, implies that education will not necessarily increase behaviour uptake. Perceived burdensomeness does not appear to play a large role.</li> </ul>
de Vries H, van Dillen S. Prevention of Lyme Disease in Dutch Children: Analysis of Determinants of Tick Inspection by Parents. Prev Med;35(2):160- 165.	Questionnaire based on the Attitude-Social Influence-Efficacy (ASE) model was developed     Doctors sent letters to parents with children ages 4-12 in a Lyme-endemic area (Netherlands)     n=230	<ul> <li>Explored factors differentiating between parents who regularly do and do not inspect their children for ticks.</li> <li>10% indicated they always check their children for nicks; 41% indicated never. Inspecting parents had more awareness about LD and tick removal, more positive cognitive attitudes (believing tick checks were important and did not require much time), a more positive emotional attitude, and a more positive moral norm towards inspection (regarding it as their duty).</li> <li>Findings imply health education programs should stress the importance of the advantages of tick checks but also need to focus on emotional aspects, such as by stressing that checks can reassure children and parents, prevent feelings of regret, and may be regarded as a parental duty.</li> </ul>
Garvin JH, Gordon TF, Haignere C, Ducette JP. Development of a public health assessment tool to prevent Lyme disease: tool construction and validation. Perspectives in Health Information Management 2005;2:11	Design and validation of Lyme disease risk assessment instrument	<ul> <li>Describes development of risk assessment tool to aid in deriving educational diagnoses as required by the PRECEDE-PROCEED model of PH planning.</li> <li>Methodology described the design and validation of a LD risk assessment instrument. Refined tool was used in a study of adult college workers in a Lyme-endemic area (Pennsylvania).</li> <li>Preventative behaviour was associated with more than perceived susceptibility and severity; additional factors included knowledge on LD, self-efficacy in undertaking prevention measures, response efficacy, beliefs, attitudes, observation of others, communication, and willingness to use learned skills.</li> </ul>
Gould LH, Nelson RS, Griffith KS, Hayes EB, Piesman J, Mead PS, et al. Knowledge, attitudes, and behaviors regarding Lyme disease prevention among Connecticut residents, 1999-2004. Vector Borne & Zoonotic Diseases 2008;8:769-776.	<ul> <li>Random cross-sectional telephone survey of 3         Connecticut health districts         n=2806     </li> </ul>	<ul> <li>Survey to evaluate impact of intensive community-wide education programs.</li> <li>84% of residents reported knowing some or a lot about LD. Proportion of respondents reporting they always performed tick checks increased by 7% and percentage using repellents increased by 5%, while those avoiding wooded areas and tucking pants into socks decreased.</li> <li>Overall, 99% of respondents reported using personal protective behaviours, compared to 65% reporting environmental controls.</li> <li>Useful description of intervention programs developed by individual health districts. Diverse methods were used, including: billboards, flyers, newspaper articles, community presentations, and internet postings. Target audiences were: the general public, school children, gardeners and outdoor enthusiasts, landscapers, and pest control companies.</li> </ul>

Herrington JE, Jr. Risk Perceptions Regarding Ticks and Lyme Disease: A National Survey. Am J Prev Med 2004;26:135-140.	National telephone survey conducted in contiguous US, over- sampling in 6 states with the highest LD incidence     n=1750	<ul> <li>Explored knowledge, perceptions, and practices on preventing tick bites and LD.</li> <li>40% of respondents indicated taking part in preventative behaviours. Less than half used repellant. Taking preventative measures was strongly associated with being very concerned about tick bites. Other predictive factors included having seen ticks, perceiving repellent as effective, having heard about LD, and knowing somebody that had LD.</li> <li>Those in high-incidence areas say LD was very serious but were less likely to adopt precautions. May reflect greater experience and information about ticks in high-incidence areas, and behaviours motivated by experience rather than fear.</li> </ul>
Hook SA, Nelson CA, Mead PS. US public's experience with ticks and tick-borne diseases: results from national HealthStyles surveys. Ticks and tick-borne diseases 2015;6(4):483-488.	<ul> <li>Data from annual, nationally-representative survey (HealthStyles) across 3 survey cycles</li> <li>n=12,281</li> </ul>	<ul> <li>Explored US public's experiences with tick-borne diseases using.</li> <li>21% of respondents reported a household member had found a tick on their body during the prior year; of those, 10.1% consulted with a HCP. 63.7% believed LD occurred where they lived, but this included 49.4% from the West South Central area and 51.1% from the Mountain regions where LD does not occur.</li> <li>Most respondents (51.2%) reported not regularly taking any preventative steps against tick bites.</li> <li>Results indicate tick exposure is common and awareness is widespread, but better understanding and use of prevention measures is needed.</li> </ul>
Marcu A, Barnett J, Uzzell D, Vasileiou K, O'Connell S. Experience of Lyme disease and preferences for precautions: a cross-sectional survey of UK patients. BMC Public Health 2013;13:481.	<ul> <li>Cross-sectional survey with early LD patients in the UK</li> <li>n=130</li> </ul>	<ul> <li>Describes awareness of having been bitten by a tick, tick and LD knowledge, interpretation of symptoms, suspicion of having LD, and precautionary actions taken.</li> <li>Almost 3/4s of participants reported a rash as the reason they sought medical advice, and almost half (44%) suspected they had LD before visiting their GP.</li> <li>Those who realized they may have been bitten by a tick were more likely to suspect LD.</li> <li>Respondents were more likely to take preventative measures after visits to the country, rather than during. The more often they visited, the less likely they were to promote during-visit precautions.</li> </ul>
Marcu A, Uzzell D, Barnett J. Making sense of unfamiliar risks in the countryside: the case of Lyme disease. Health Place 2011;17:843-850.	<ul> <li>Semi-structured interviews conducted in 3 parks in the UK</li> <li>n=66</li> </ul>	<ul> <li>Explored representations of the countryside among countryside users, and how those representations help them develop an understanding of risks (i.e. LD).</li> <li>Social representations theory was used as a framework to explore how participants constructed meanings about the risk of LD.</li> <li>Three major themes emerged: of the countryside as a restorative place, the everyday experiences of the countryside, and constructing a countryside identity.</li> <li>LD was not considered primarily a risk to health; risk was juxtaposed against the idyll of the countryside and thus characterized as unlikely to impact a visitors' regular use of the countryside.</li> <li>Spending a lot of time in the country without having contracted LD was used to support participants' claims of not considering themselves at risk.</li> <li>Constructing an identity for one's self as a 'country person' and never having heard of the disease justified one's lack of precautionary action. Activities such as long sleeves were portrayed as intrusive, and against the immersion in common country practices.</li> <li>Comments from respondents suggest advice about LD and other zoonoses should focus on the least intrusive preventative measures when communicating risks. Communication of risks did not have a 'panic' effect that drove people away from the outdoors; rather, advice was ignored as intrusive with the enjoyment of the countryside.</li> </ul>

McKenna D, Faustini Y, Nowakowski J, Wormser GP. Factors influencing the utilization of Lyme disease-prevention behaviors in a high-risk population. J Am Acad Nurse Pract 2004;16:24-30.	<ul> <li>Questionnaire completed by patients presenting to the LD Diagnostic Center in New York state</li> <li>n=219</li> </ul>	<ul> <li>Explored factors that motivated people at high risk of LD to implement prevention behaviours.</li> <li>Those who reported having LD in the past or those who had a family member or friend with LD were more likely to use preventative behaviours. Findings imply younger individuals without a history of LD should be targeted for educational programs about LD.</li> <li>Patients considering themselves high risk enough to self-refer to a LD clinic did not consistently perform preventative behaviours, suggesting their underutilization.</li> </ul>
Mowbray F, Amlot R, Rubin GJ. Predictors of protective behaviour against ticks in the UK: a mixed methods study. Ticks Tick Borne Dis 2014;5(4):392-400.	<ul> <li>Mixed-methods approach</li> <li>Qualitative interviews with experts (n=13) used to identify effective prevention methods</li> <li>Qualitative interviews with members of the public (n=25) conducted to identify motivational factors</li> <li>Quantitative web survey assessed preventative behaviours among members of the public (n=343)</li> </ul>	<ul> <li>Examined which preventative behaviours against LD were most appropriate to promote among those at higher risk of contracting LD (members of an outdoor group).</li> <li>Tick checks were chosen as the main outcome variable because it was viewed as less likely than other behaviours to be inhibited by barriers such as safety concerns (e.g. repellent use) or social norms (e.g. tucking pants into socks).</li> <li>A lack of time and forgetfulness were barriers to tick-checking. Strongest predictors of tick-checking were greater levels of knowledge, perceived likelihood of encountering a tick, removal confidence (self-efficacy), and lower levels of disgust.</li> </ul>
Shadick NA, Daltroy LH, Phillips CB, Liang US, Liang MH. Determinants of tick-avoidance behaviors in an endemic area for Lyme disease. Am J Prev Med 1997;13:265-270.	<ul> <li>Cross-sectional survey of ferry commuter passengers in Massachusetts (Martha's Vineyard, a Lyme- endemic area)</li> <li>n=304</li> </ul>	<ul> <li>Respondents described their knowledge and performance of tick-avoidance behaviours.         Respondents had adequate knowledge of LD, but fewer reported use of preventative behaviours.         Determinants of behaviours were determined to be perceptions of the behaviour's benefits outweighing its inconvenience, confidence in the ability to recognize LD symptoms, believing LD is a serious illness, and believing preventative behaviours are effective. Increased knowledge of LD did not predict performance of behaviours.     </li> <li>Interesting implications for prevention programming, as increased knowledge is not correlated with higher self-confidence. Program development will have to explore ways to improve perceptions of efficacy and confidence.</li> <li>Despite the majority of respondents believing preventative behaviours would put their minds at ease, more than half also felt they would be "a hassle".</li> </ul>

Tadiri C, Ainsworth N, de Bono N, Gavin S, Jun L, Milbers K, et al. Assessment of human health risk for Lyme disease in a peri-urban park in southern Quebec. McGill Science Undergraduate Research Journal 2011;6:56-61.	•	Exit surveys of park-goers in a peri-urban park in southern QB n=103	•	Exploratory study to examine factors associated with LD.  Surveys asked about spatial use of the park, patterns of behaviours, and LD awareness.  45.6% of respondents reported awareness of tick precautions, but only 28.1% reported actually employing any on that day.  20% of the sample reported going off-trail, which could be a potential source of risk.  Results showed higher awareness among females (consistent with US studies), park-goers over age 50, and high-frequency users.
Valente SL, Wemple D, Ramos S, Cashman SB, Savageau JA. Preventive behaviors and knowledge of tick-borne illnesses: results of a survey from an endemic area. Journal of Public Health Management & Practice 2015;21:E16-23.	•	Survey to participants in Martha's Vineyard, MA n=946	•	Assesses knowledge and preventative behaviours around LD in an endemic area, to update prior studies and examine how sociodemographic data correlated with behaviours.  Results showed poor knowledge of tick-borne illnesses and low practicing of preventative behaviours. Most common behaviour was tick checking, by 45%; least frequent was using tick repellents (10%).  The two high-risk groups (youth and outdoor workers) reported little prevention behaviours. Youth reported the lowest frequency of preventative behaviours, which did not correlate with an increased perception of risk.  Findings demonstrated high-risk groups have low knowledge of tick-borne diseases and practice little preventative measures. Youth may be challenging to convince, based on findings that their perception of risk did not impact performing any prevention behaviours.

# Patient/public education — sources on the topic of presenting information to patients or the public.

Reference		Methodology		Article summary
Anderson A, Chaney E. Tickassociated diseases: symptoms, treatment and prevention. American Journal of Health Education 2009;40:183-189.	•	Descriptive overview	•	Discusses how to educate the public on personal protection.  Approaches are more successful when coupled together (e.g. a media campaign together with community-based programs, rather than just a media campaign alone).  Communication should be across many settings (schools, community, work and healthcare settings) and be audience-centred. Specific population segments targeted should provide insights into their preferred channels and formats of delivery.  The process should involve: audience analysis; developing the message; identifying credible sources of information; and determining the channels for communication.
Cooper JD, Feder HM,Jr. Inaccurate information about Lyme disease on the internet. Pediatr Infect Dis J 2004;23(12):1105-1108.	•	Website review	•	Reviewed accuracy of LD information easily accessible on the web.  15 search engines were used to find 251 LD websites. After review, 19 sites gave general LD information that was analyzed, exploring the accuracy of 8 LD topics.  10 of 19 sites gave accurate information, 9 provided inaccurate information. 8 websites contained 'Lyme' in their name; 7 had inaccurate information. 2 '.gov' sites contained accurate information. Important to realize patients may come to physicians having done research on LD on the internet, and they may have encountered misinformation.

Hartmann J. Infectious diseases on the World Wide Web. Med Ref Serv Q 2004;23:49-60.		<ul> <li>Comments on the vast amount of information available on the internet on infectious diseases – much of which may be unreliable.</li> <li>Lists best websites on various infectious diseases in order to help both practitioners and patients find current, accurate information.</li> <li>The criteria used to select sites were: 1) free access; 2) authorship by reputable organizations; 3) comprehensiveness, covering the topic in detail; 4) currency; 5) ease of use; and 6) topicality.</li> </ul>
Marzano M, Moseley D, Quine CP, Barnett J. Organisational intentions and responses: presenting the risk of Lyme disease to countryside users. Journal of Environmental Planning & Management 2013;56:305-328.	<ul> <li>Semi-structured interviews</li> <li>n=19</li> </ul>	<ul> <li>Explores risk communication around LD among organizations who wish to prevent either their staff or the general public from contracting the disease.</li> <li>Interviews conducted with representatives of land use organizations, to learn about the issues they faced when communicating risk.</li> <li>Organizations were also requested to provide some of their communications materials and documents, which underwent a descriptive content analysis.</li> <li>Varying opinions on the seriousness of LD risk, thought to be less than other countryside hazards.</li> <li>No clear agreement on what level of information should be communicated how and to whom, although there was a call for a consistent approach.</li> <li>Little connection or collaboration between health authorities (who may be considered responsible for disease prevention, and sources of expert medical knowledge) and land use organizations that interact directly with users of the countryside.</li> </ul>
Sood SK. Effective Retrieval of Lyme Disease Information on the Web. Clinical Infectious Diseases 2002;35(4):451-464.	Website review	<ul> <li>Accurate information on LD may be hard to find on the web, as there exists a controversy on the subject.</li> <li>Article discusses legitimate online resources, with several sites undergoing review.</li> <li>Not only are legitimate resources important for physicians to access in order to obtain proper information, but they will then be able to direct patients to such resources as well.</li> </ul>

# Health promotion campaigns, educational interventions – sources describing or evaluating Lyme disease programs.

Reference	Methodology	Article summary
Corapi KM, White MI, Phillips CB, Daltroy LH, Shadick NA, Liang MH. Strategies for primary and secondary prevention of Lyme disease. Nat Clin Pract Rheumatol 2007;3(1):20-25.	Descriptive overview	<ul> <li>Discusses primary and secondary prevention strategies for LD. Uptake has been universally poor.</li> <li>Research in endemic areas has shown that although the population may have adequate knowledge about LD, people do not perform preventative behaviours.</li> <li>Based on the Health Belief Model, recommended that public health strategies should increase people's confidence in abilities to perform behaviours and increase awareness of positive outcomes.</li> </ul>

Daltroy LH, Phillips C, Lew R, Wright E, Shadick NA, Liang MH. A controlled trial of a novel primary prevention program for Lyme disease and other tickborne illnesses. Health Education & Behavior 2007;34:531-542.	<ul> <li>Randomized control trial of educational intervention</li> <li>n=30,164</li> </ul>	<ul> <li>Describes an educational program to prevent LD and other tick-borne illnesses (TBI), delivered to ferry passengers travelling to an endemic area in SE Massachusetts.</li> <li>Rates of TBI and tick checking behaviours were measured over 3 summers in ~30,000 passengers. There were lower TBI rates in those who received education compared with control group participants who received bicycle safety education, and 60% reduction in risk for those visiting Nantucket Island for more than 2 weeks.</li> <li>Educated participants were more likely to take precautions (repellent, clothing) and check for ticks. Demonstrates a relatively inexpensive health education message can be delivered to an at-risk population and result in increased precautionary behaviours.</li> <li>This was one of the few RCTs found in the literature review.</li> </ul>
Gray JS, Granstrom M, Cimmino M, Daniel M, Gettinby G, Kahl O, et al. Lyme borreliosis awareness. Zentralblatt fur Bakteriologie 1998;287:253-265.	<ul> <li>Material development</li> <li>Feasibility study</li> </ul>	<ul> <li>A LD information leaflet was designed by EUCALB to standardize educational material across different European countries.</li> <li>Complements a questionnaire designed to measure LD awareness, which can be used before and after educational interventions in order to determine their impact.</li> <li>The leaflet did improve performance on the questionnaire, but only tested on students and has not been evaluated among the general public.</li> </ul>
Lawless KA, Brown SW, Cartter M. Applying Educational Psychology and Instructional Technology to Health Care Issues: Combating Lyme Disease. Int J Instr Media 1997;24(4):287-297.	Randomized control trial	<ul> <li>Examined effects of an instructional video on knowledge, attitudes, and beliefs of high school students re: LD.</li> <li>The intervention involved a video ("The Curse of the Blood Suckers"), 16 minutes in length and specifically designed for high school students by using a horror movie theme.</li> <li>All students were administered a pre-test survey to determine baseline knowledge; the treatment group then received the video. A post-test survey was completed approximately 1 month later, with a third survey administration 6 months after the video.</li> <li>Was an increase in knowledge as a result of the intervention, but less positive results in the longer term on attitudes and behaviours. Knowledge effects also weakened over time.</li> </ul>
Malouin R, Winch P, Leontsini E, Glass G, Simon D, Hayes EB, et al. Longitudinal evaluation of an educational intervention for preventing tick bites in an area with endemic Lyme disease in Baltimore County, Maryland. Am J Epidemiol 2003;157(11):1039-1051.	<ul> <li>Randomized control trial</li> <li>n=317</li> </ul>	<ul> <li>Evaluated targeted educational intervention in an endemic Lyme area to determine whether knowledge, attitudes, and behaviours around tick bite prevention could be increased.</li> <li>Subjects in Baltimore were randomized to receive bimonthly educational materials via mail – either general health-related materials or tick-related (education on performing tick checks, identifying and removing ticks, and applying repellants; these were identified as most feasible and acceptable behaviours via focus group interviews).</li> <li>At each of 3 clinic visits, participants completed a self-administered questionnaire and provided a serum sample (to measure a biomarker of tick bites).</li> <li>Desired responses related to tick checks and insect repellent use increased significantly among subjects receiving the intervention. Knowledge/attitude/behaviour measures had greater changes between visits 1 and 2, the period where most repellent-related intervention materials were sent out and when people were most engaged in outdoor activities. Intervention wasn't associated with antibody measures; the tick bite measure did have some limitations however.</li> <li>One of the few RCTs on LD interventions in the literature; even fewer actually use a measure other than self-report to measure outcomes.</li> </ul>

Mowbray F, Amlot R, Rubin GJ. Ticking all the boxes? A systematic review of education and communication interventions to prevent tick- borne disease. Vector Borne Zoonotic Dis 2012;12(9):817-825.	Systematic review	<ul> <li>A systematic review of studies that assessed the impact of behavioural or educational interventions around preventive behaviours for tick-borne diseases (TBDs).</li> <li>Searching for such studies turned up few results (9 studies), and only 2 of these were RCTs. Most did not explicitly note any psychological theories on how to best promote protective health behaviours.</li> <li>Results indicate that knowledge and attitudes towards TBDs are amenable to change, although the lasting impact of these changes has yet to be determined.</li> <li>Studies have shown shifts in the use of insecticides, tick checking, and avoiding tick areas; there were also changes in knowledge and attitudes towards ticks, diseases, and preventative behaviours. Authors call for more theoretically-based, methodologically-robust studies.</li> </ul>
van Velsen L, Beaujean DJMA, Wentzel J, Van Steenbergen JE, van Gemert-Pijnen, Julia E. W. C. Developing requirements for a mobile app to support citizens in dealing with ticks and tick bites via end-user profiling. Health Informatics Journal 2015;21:24-35.	<ul> <li>In-depth interviews         (n=25)</li> <li>Focus group</li> </ul>	<ul> <li>Describes process of creating a mobile app to support people dealing with ticks and tick bites.</li> <li>Involved identifying organizational stakeholders, identifying end-user profiles, and determining the app requirements.</li> <li>A risk analysis segmented the population into outdoors people, parents/children, and professionals in the green sector (e.g. gardeners, foresters). Interviews with these groups were conducted in order to tailor the app towards the end-user's needs and wishes, creating 'personas'.</li> <li>Some findings could be applied to other messaging, such as users wanting to be informed tick risks and how they should deal with them, but still wanting to enjoy nature in a carefree manner. Providing information at the appropriate time and place was important, such as by alerts based on GPS, seasonality, and end-of-day reminders to check for ticks.</li> </ul>

### **Prevention methods and information** – sources dealing with Lyme disease prevention and precautionary measures.

Reference		Methodology		Article summary
Aenishaenslin C, Hongoh V, Cisse HD, Hoen AG, Samoura K, Michel P, et al. Multi-criteria decision analysis as an innovative approach to managing zoonoses: results from a study on Lyme disease in Canada. BMC Public Health 2013;13:897.	•	Multi-criteria decision analysis model development	•	Compared interventions for managing LD in Quebec.  Analyses were developed for surveillance and control interventions, and an emergence versus epidemic scenario.  Preferred surveillance interventions: active surveillance of vectors by flagging or dragging, active surveillance of vectors by trapping small rodents and passive surveillance of vectors of human origin.  Preferred control interventions were: basic preventive communications, human vaccination and small scale landscaping.  Emerging versus epidemic scenarios only had a small effect on ranking the interventions in the control model.
Del Fabbro S. Fencing and mowing as effective methods for reducing tick abundance on very small, infested plots. Ticks & tickborne Diseases 2015;6:167-172.	•	Intervention comparison at 3 sits in northeastern Italy	•	Explored strategies for reducing risk of tick bite by assessing two simple interventions for reducing tick abundance around residential properties surrounded by wooded areas (conducted in a Lymeendemic area).  Fencing and mowing small surfaces were evaluated alone and in combination.  Fencing can prevent the entrance of tick hosts and decreases tick abundance in a short time; mowing contributes as well. These are safe, simple, cheap, and effective interventions methods even when close to heavily infested woodlands.

Hakim JA, Bitto A. Public education and Lyme disease prevention in Monroe County: a multi-faceted program of personal protection strategies, tick identification/risk assessment, bi-directional referrals, and vector control. Californian Journal of Health Promotion 2005;3:137-145.	Program description	<ul> <li>Describes a 6-year LD prevention program in Pennsylvania, in a hyper-endemic county.</li> <li>Members of the community bitten by ticks and seeking medical care were directed to Monroe Country Vector Control (MCVC) by physicians. Those bitten by ticks bring samples to the MCVC for identification and risk assessment.</li> <li>Risk assessment involves identifying the tick specials and life stage. Body parts ratio also measured to determine engorgement; value is entered into a regression analysis tool to determine hours of attachment to provide information on whether to treat patients who have been bitten by nymphal or female tacks that approach 48 hours attachment.</li> <li>They receive counselling, health education (re: tick ecology, removal techniques, personal protection), and if needed, medical referral.</li> <li>Low numbers of LD cases relative to the number of LD-positive ticks and bites indicate that these prevention strategies are working.</li> <li>This approach allows physicians to only consider individuals who meet the criteria of suspected LD exposure, and protects non-at-risk individuals from unnecessary treatment. Identification and risk analysis can be done at any health department; it only requires a medium-powered microscope, basic training on tick anatomy, a taxonomic key of species in an area, the regression equation, and epidemiological data on the local tick infection rates.</li> </ul>
Ogden NH, Lindsay LR, Schofield SW. Methods to Prevent Tick Bites and Lyme Disease. Clin Lab Med 2015;35:883-899.	Descriptive overview	<ul> <li>Review article discussion various prevention methods for LD: avoiding risk areas, applying personal protective measures, reducing environmental risks, and using prophylactic antibiotics.</li> <li>An excellent overview of preventative measures all in one place, current and applicable to both American and Canadian contexts.</li> <li>Criteria for assessing LD risk is especially helpful, as this is what physicians must consider when deciding whether to prescribe post-bite prophylaxis.</li> </ul>
Piesman J, Eisen L. Prevention of Tick-Borne Diseases. Annu Rev Entomol 2008;53:323-343.	Descriptive overview	<ul> <li>Reviews prevention for tick-borne diseases, including knowledge of spatiotemporal risk patterns for exposure, personal protective measures, suppression of tick hosts, suppression of infected ticks, and avoiding disease after bites.</li> <li>The importance of web-based information resources that provide two-way flows of information is stressed.</li> <li>Risk maps are suggested for inclusion on such sites, as they can be used for decision-support tools for both the public and medical practitioners.</li> </ul>

# **Resources** – sources and materials created for promotional or educational purposes.

Reference	Article summary
Centers for Disease Control and	CDC Lyme pages are the most referenced and linked-to sources amongst the American-based (and international) resources found.
Prevention. (2015). Lyme disease.	This would be the main authority for disease information.
Retrieved from	• Topics include: prevention (on people, pets, and in the yard); tick removal and testing; transmission; signs and symptoms; diagnosis
http://www.cdc.gov/lyme/index.h	and testing; treatment; post-treatment Lyme disease syndrome; FAQs; information for healthcare providers; and educational
<u>tml</u>	materials.
	• Some educational materials available for download include fact sheets (in multiple languages) for outdoor workers, hikers, golfers,
	pregnant women and parents; trail signs; a comic and crossword puzzle for children; and radio PSAs.
Centers for Disease Control and	The CDC's guide to tick-borne diseases for HCPs.
Prevention. (2015). Tickborne	Multiple diseases covered.
diseases of the United States: A	Risk area maps are US-only, but LD info is appropriate.
reference guide for health care	Brief, to-the-point, colourful and well-presented.
providers. Atlanta, GA: US	Very good images of erythema migrans variations.
Department of Health and	, , , , , , , , , , , , , , , , , , , ,
Human Services, CDC.	
Centers for Disease Control and	CDC has developed a phone app (both iOS and Android) to serve as a quick reference guide for HCPs.
Prevention. (2015). Tickborne	• Includes information on tick identification, risk areas, signs and symptoms, ordering lab tests, and proper treatment.
diseases - app. Atlanta, GA: US	There does not appear to be a version for patients.
Department of Health and	
Human Services, CDC.	
https://itunes.apple.com/WebO	
bjects/MZStore.woa/wa/viewSof	
tware?id=961113666&mt=8	
European Centre for Disease	This toolkit was developed to help EU Member States in devising communication activities to raise awareness about the health
Control and Prevention. (2015).	This toolkit was developed to help EU Member States in devising communication activities to raise awareness about the health threats related to ticks, as well as promoting preventive measures to reduce the risk of tick-borne diseases.
Communication toolkit on tick-	<ul> <li>Key messages are aimed for 4 specific audiences: children, travelers, general public living in endemic areas, and HCPs.</li> </ul>
borne diseases. Retrieved from	<ul> <li>Ney messages are affice for 4 specific addictions, travelers, general public living in endeffic areas, and ners.</li> <li>Materials designed to be adapted for local contexts, provided in various file formats and for various TBDs.</li> </ul>
http://ecdc.europa.eu/en/health	
topics/emerging and vector-	Gommanious Burse has executed in our matter of commandations of utage, and utage,
borne diseases/tick borne dise	<ul> <li>Timing (such as seasonal factors, existing awareness campaigns and news stories)</li> <li>Price (both budget and costs)</li> </ul>
ases/public health measures/pa	
ges/communication toolkit.aspx	<ul> <li>Products (types of materials used in the communications which can also include physical products - such as insect repellents - or services - health checks)</li> </ul>
	<ul> <li>Distribution (how and where to circulate the messages/materials)</li> </ul>
	<ul> <li>Additional channels (incorporating advertising, public relations, promotions and media advocacy)</li> </ul>
	<ul> <li>Potential allies/partnerships (such as schools, hospitals and health clinics, pharmacies, medical associations, travel companies,</li> </ul>
	airlines, airport authorities, camping sites, outdoors sports centres, etc.)

European Centre for Disease Control and Prevention. (2015). National communication campaigns and materials on tick- borne diseases. Retrieved from http://ecdc.europa.eu/en/health topics/emerging and vector- borne diseases/tick borne dise ases/campaigns- information/Pages/campaigns- and-information.aspx	•	This website lists some examples of national TBD campaigns, mostly linking out to their websites.  Some interesting examples are a phone app for tick identification and registering tick bites, and a Netherlands tick radar website (unfortunately no English translation available).
Guide to care for patients: Lyme disease. (2004). Nurse Practitioner, 29, 41-42 2p. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=nyh&AN =14006721&site=ehost-live	•	Patient resource re: LD – a foldable pamphlet with room for HCP's business card. Encouraged to be photocopied and distributed to patients.
Infectious Disease Society of America. (2015). Lyme disease case study course. Retrieved from http://lymecourse.idsociety.org/	•	A physician resource in the form of a case study course for continuing medical education (CME) units.  Case studies are based on IDSA guidelines and designed to educate clinicians on diagnosis and treatment.
Maine Center for Disease Control & Prevention. (2015). Lyme disease. Retrieved from http://www.maine.gov/dhhs/mecdc/infectious-disease/epi/vector-borne/lyme/index.shtml	•	The website for the Maine CDC focuses on its own local context, but does have links to interesting resources  E.g. there has been a school curriculum developed for 3rd – 5th grade classrooms, which includes a presentation, interactive games, take-home activity book, and a fact sheet.
Ontario Ministry of Health and Long-Term Care. (2015). Lyme disease is in Ontario. Retrieved from http://www.health.gov.on.ca/en /ms/lyme/default.aspx	•	The MOHLTC landing page for Lyme disease, which funnels the user in two directions – one way for information for the public, the other way for health professionals.  Pages are very brief, and link to other resources (e.g. PHAC, CDC).

Patient notes: Lyme disease. (2005). <i>Postgraduate Medicine</i> , 117, 47-48.	<ul> <li>Patient resource re: LD, encouraged to be photocopied and distributed to patients by physicians.</li> <li>Creative and unique approach, different than the usual standard articles in medical journals.</li> </ul>
Page for patients. Lyme disease. (2001). <i>Preventive Medicine</i> , <i>32</i> , 453-454.	<ul> <li>Patient resource re: LD.</li> <li>Unappealing –all text, no colours or images, not well formatted Example of what not to do.</li> </ul>
Public Health Agency of Canada. (2016). Lyme disease. Retrieved from http://healthycanadians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/lyme/index-eng.php	<ul> <li>PHAC's landing page for Lyme disease information.</li> <li>Repository of general information on LD, including: causes, symptoms, risks, treatment and testing, prevention, surveillance, tick removal and submission, a page for health professionals, and awareness resources.</li> <li>Information is fairly general, as it covers Canada generally, with some specific references to individual provincial needs (e.g. risk areas, testing).</li> <li>Resources include: a video; a prevention toolkit (pdf booklet); posters; a handout; a pamphlet; web banners; and Facebook posts and images</li> </ul>
Public Health Ontario. (2015). Lyme disease. Retrieved from <a href="http://www.publichealthontario.ca/en/BrowseByTopic/InfectiousDiseases/Pages/IDLandingPages/Lyme-Disease.aspx">http://www.publichealthontario.ca/en/BrowseByTopic/InfectiousDiseases/Pages/IDLandingPages/Lyme-Disease.aspx</a>	<ul> <li>PHO's landing page for Lyme disease information.</li> <li>Contains information current and relevant for Ontario, including tick identification and testing, reporting forms, risk maps, surveillance reports, and links to other resources.</li> </ul>
Ridgefield, Connecticut. (2008). BLAST! Lyme disease prevention program. Retrieved from http://www.ridgefieldct.org/cont ent/46/6311/6347/8905.aspx	<ul> <li>The website for the BLAST! Lyme disease program, developed by the town of Ridgefield, Connecticut in 2008.</li> <li>Program raises awareness of prevention practices and educations the community about signs and symptoms of LD.</li> <li>Involves presentations to schools and other organizations, and distributes information at community events, fairs, and festivals. Materials available on the website include presentations (though with American stats), brochures, and flyers.</li> <li>BLAST stands for 5 steps: B – bathe or shower after coming in from outdoors; L – look for ticks and rashes; A – apply repellents; S – spray your yard; T – treat your pets to prevent tick bites. These are all scientifically supported activities based on research from the Connecticut Emerging Infections Program at Yale University.</li> </ul>
University of Rhode Island. (2016). Tick encounter resource center. Retrieved from http://www.tickencounter.org/	<ul> <li>Website with interesting features, such as updating current tick activity in different areas and providing information on identifying and testing ticks.</li> <li>Focused on the US, but some aspects, such as a particularly strong tick identification guide, applicable to other contexts.</li> <li>Also describes the TickSmart campaign, a program focused on educating people at risk on strategies for tick-safe living. Some of the products are interesting, creative (e.g. shower cards, toilet stall cards, identification magnets), and can be ordered and customized with organizational logos.</li> </ul>
Zeller, J. L. (2007). Lyme disease. JAMA: Journal of the American Medical Association, 297, 2664- 2664.	<ul> <li>Patient page for Lyme.</li> <li>Brief presentation of the general information.</li> <li>Example of patient-geared information in a professional journal.</li> </ul>