



LYME DISEASE IN CANADA

A DRAFT FEDERAL FRAMEWORK



I. PREAMBLE

The current state of knowledge about Lyme disease and the need to increase the evidence base have brought diverse stakeholders together to work toward a common goal of preventing Canadians from acquiring Lyme disease, and supporting Canadians already affected.

The Conference to Develop a Federal Framework on Lyme Disease, held in May 2016, brought Lyme disease patients, representatives of federal, provincial and territorial health ministries, patient groups, researchers, and health care providers together to exchange their views, share the latest available scientific evidence, and make recommendations on the path forward.

Input from all representatives was considered in the development of this Framework, which is intended to help guide a way forward in those areas in which the Government of Canada has a role. It is expected that the Framework will promote the involvement of all stakeholders, including patients and their representatives, in continuing dialogue to adapt as new evidence is discovered. Progress on actions will be reported, on an ongoing basis.

II. INTRODUCTION

Lyme disease is an infectious illness caused by the bacterium *Borrelia burgdorferi* (*B. burgdorferi*). This bacterium is transmitted to people through the bite of infected blacklegged ticks (*Ixodes scapularis*) in parts of Eastern and Central Canada, and the western blacklegged tick (*Ixodes pacificus*) in parts of the Pacific region. Many species of ticks in Canada do not transmit *B. burgdorferi*, such as the dog tick.

The geographic distribution of the blacklegged tick has expanded in Canada since 2004 (Figure 1). As ticks can attach themselves to birds, they can also be found in other areas across Canada. Unlike other areas in Canada, blacklegged tick populations have remained stable in British Columbia over the past decade. Canadian public health authorities at all levels of government are coordinated in the effort to monitor the spread of the ticks that can transmit Lyme disease, as well as the cases of Lyme disease among Canadians exposed to these ticks.

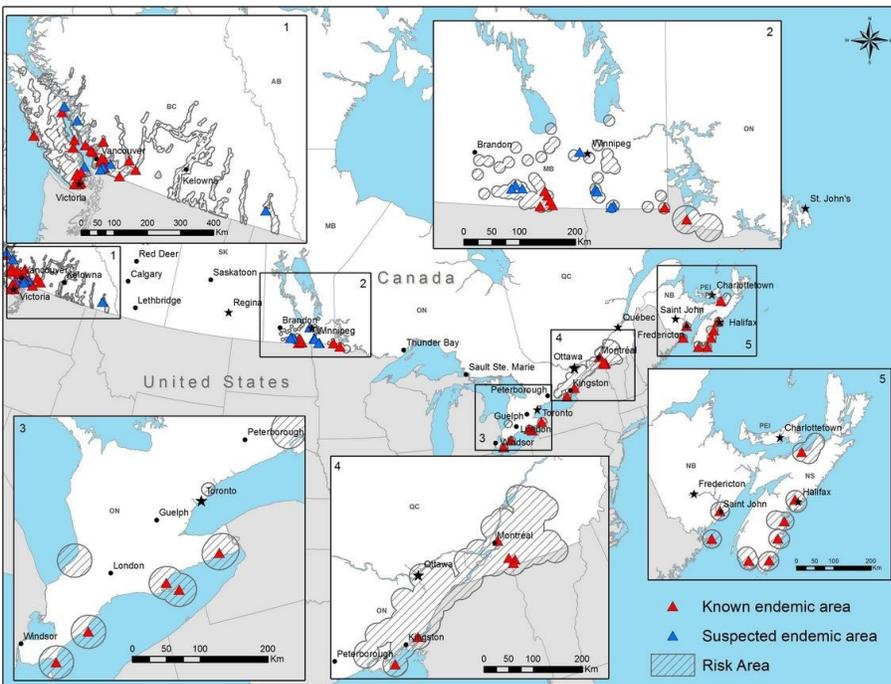


Figure 1: Lyme disease risk areas in Canada where ticks and *B. burgdorferi* are most likely endemic as of 2016. (1)

The number of confirmed human cases in Canada has been growing steadily since Lyme disease became nationally notifiable in 2009 (see Figure 2). The risk of Lyme disease occurs mainly in or near areas where tick populations that transmit the bacterium are established. Blacklegged ticks are active through much of the year. However, bites leading to human infection are much more common during the spring and summer months. The risk is highest in people engaging in occupational or leisure activities, such as camping and hiking, near or in forested or semi-forested areas where the ticks are found. Exposure to ticks can occur in other circumstances, such as gardening, golfing or dog walking if these occur in locations where ticks are found.

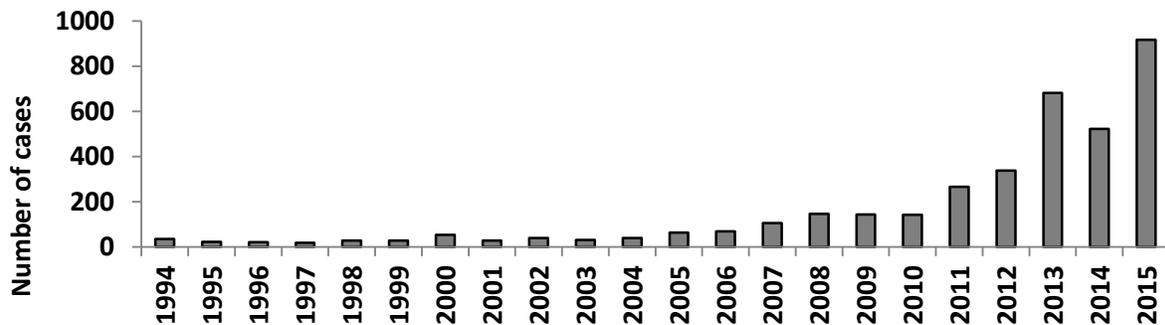


Figure 2: Number of human cases of Lyme disease reported in Canada, 1994-2015, compiled from a number of sources. (2)

III. AN ACT RESPECTING A FEDERAL FRAMEWORK ON LYME DISEASE

An Act respecting a Federal Framework on Lyme Disease (3), which received Royal Assent in December 2014, requires the Federal government to develop a Federal Framework on Lyme Disease that would include the following three pillars:

- **Surveillance:** The establishment of a national medical surveillance program to use data collected by the Public Health Agency of Canada to properly track incidence rates and the associated economic costs of Lyme disease.
- **Guidelines and Best Practices:** The establishment of guidelines regarding the prevention, identification, treatment and management of Lyme disease, and the sharing of best practices throughout Canada.
- **Education and Awareness:** The creation and distribution of standardized educational materials related to Lyme disease, for use by any public health care provider within Canada, designed to increase national awareness about the disease and enhance its prevention, identification, treatment and management.

To inform the development of this Framework, the Public Health Agency of Canada, on behalf of the Minister of Health, held a Conference in May 2016. Over 500 people participated in person and via an online interface. Lyme disease patients, their families and others shared their experiences with Lyme disease. In addition, Lyme disease experts provided information on current knowledge and research related to Lyme disease treatment, prevention, diagnosis and management. The full [Conference Summary Report](#) can be accessed online.

IV. A SHARED FEDERAL RESPONSIBILITY

The Government of Canada plays a national leadership role in helping to reduce the risk to Canadians posed by infectious diseases. It fulfils this role by tracking and monitoring infectious disease threats, undertaking research, preventing and controlling the spread of disease, promoting healthy behaviours, brokering knowledge transfer, and facilitating innovation.

Several federal government departments and agencies are involved in addressing Lyme disease in Canada:

The **Public Health Agency of Canada**, as the Government of Canada's lead for public health, has focused efforts on tracking the incidence of Lyme disease nationally, increasing Lyme disease awareness among Canadians and front-line health professionals, monitoring the distribution and expansion of the Lyme disease risk in Canada to enhance prevention and control, and ensuring national consistency and standards in diagnosis across the country.

The **Canadian Institutes of Health Research** is the Government of Canada's health research funding agency, with a mandate to support the creation of new knowledge and its translation to various health areas including Lyme disease. For Lyme disease in particular, CIHR has supported work on the mode of action of *B. burgdorferi*, looking specifically at its molecular biology, virulence factors and pathogenicity.

Within **Health Canada**, the First Nations and Inuit Health Branch supports the delivery of public health and primary health care services, including those related to Lyme disease, to on-reserve First Nations communities. The Health Products and Food Branch is responsible for licensing diagnostic test kits, which are used by doctors to support a clinical diagnosis of Lyme disease.

The **Pest Management Regulatory Agency** is responsible for the pre-market evaluation and post-market monitoring of all pest control products, including those that are used to repel and control ticks.

The **Department of National Defense (DND) /Canadian Armed Forces (CAF)** is responsible for the delivery of health care services to CAF personnel in Canada and around the world. The DND/CAF, often in consultation with federal, provincial/territorial and local health partners, develops evidence-based policies, programs and interventions to prevent and manage Lyme disease among its military members, and to, as appropriate, support education and prevention programs for its civilian personnel.

Parks Canada raises awareness of Lyme disease risks in National Parks, National Historic Sites and National Marine Conservation Areas through the distribution of Lyme disease prevention/awareness materials.

Much of this work is done in partnership with provincial, territorial and Indigenous public health authorities, and with health professionals and researchers in the private sector, non-government sector and academia.

V. WORKING WITH CANADIAN AND INTERNATIONAL PARTNERS

In Canada, protecting Canadians against Lyme disease requires collaboration among all levels of government, as well as non-governmental organizations. As guided by the provisions of the *Canada Health Act*, provinces and territories are primarily responsible for the delivery of both direct health care services and public health activities. Provincial and territorial public health authorities undertake prevention and control activities specific to their own jurisdictions. This work is often in collaboration with professional and non-governmental organisations.

In the U.S., Lyme disease is transmitted by the same ticks that occur in Canada and is the most commonly reported vector-borne illness, with most cases reported in the northeastern and upper mid-western states. It is estimated that the number of people diagnosed with Lyme disease each year in the U.S. is approximately 300,000 (4). Lyme disease also occurs in Europe and Asia, where ticks similar to those found in Canada are responsible for transmission of the disease. As in Canada, the number of cases in Europe is increasing, with higher incidence in parts of Slovenia, Germany, Austria and states bordering the Baltic Sea (5).

PHAC collaborates with public health organizations in other countries, such as the U.S. Centers for Disease Control and Prevention (U.S. CDC) and the European Centre for Disease Prevention and Control (ECDC), to exchange surveillance information, share research findings and learn about current practices to prevent and control Lyme disease.

VI. SCOPE

Under this Framework, the Government of Canada will focus activities outlined under the three pillars of: 1) surveillance; 2) guidelines and best practices; and 3) education and awareness. In addition, the framework is grounded on key principles as follows:

- **Engagement and Collaboration:** Advancing action on Lyme disease requires the involvement and collaboration of Lyme disease patients and their families, patient groups, health care providers, public health authorities, expert researchers, and federal, provincial and territorial governments.
- **Evidence-based:** Identifying action to address current challenges related to Lyme disease should be based on the best available evidence, supplemented by input from all stakeholders, including Lyme disease patients. There is a need for ongoing dialogue and discussions to build consensus on the prevention and control of Lyme disease.
- **Adaptability:** Action on Lyme disease should be adapted to respond to new surveillance and research results. Building a common understanding as new information becomes available amongst all stakeholders will be essential to moving forward in a coherent and collaborative fashion.

A. SURVEILLANCE

Surveillance is essential to understanding the magnitude of the risk posed to Canadians. This involves monitoring both the distribution and spread of blacklegged ticks that carry the pathogen *Borrelia burgdorferi*, and tracking human cases of the disease across the country.

Lyme disease in humans has been a nationally notifiable disease since 2009. Nationally notifiable diseases are infectious diseases that have been identified by the federal government and all provinces and territories as priorities for monitoring and control efforts. Data on these cases inform analyses of national and provincial trends in Lyme disease. PHAC's Lyme Disease Enhanced Surveillance (LDES) system, initiated in 2010, aims to better identify where Lyme disease cases are occurring in Canada, what populations are most at risk, and information on the types of Lyme disease that are being reported in different jurisdictions.

Strengthen national surveillance system for Lyme disease.

Federal and provincial public health authorities will continue to build on surveillance activities through collaboration with partners to develop new surveillance methods and share expertise. Tick surveillance in national parks, historic sites and on-reserve Indigenous communities, and the use of electronic tools should be considered to inform the production of risk maps to reflect region-specific information as the distribution of ticks capable of transmitting the disease changes.

Track the associated economic cost of Lyme disease.

The increase in the distribution and number of individuals affected by Lyme disease in Canada is having a financial impact on the health care system. An analysis of costs should be considered, including both direct and indirect costs, where possible.

B. GUIDELINES AND BEST PRACTICES

Guidelines and best practices that are evidence-based and effectively targeted to reach specific groups will be critical to address Lyme disease.

Strengthen the sharing of best practices to prevent Lyme disease.

FOCUS ON PREVENTION

Currently, the best way to protect against Lyme disease is to prevent tick bites. Prevention and awareness programs are implemented by local public health authorities and other health care/veterinary providers to raise awareness of the risks of Lyme disease and measures to protect against tick bites. Work with stakeholders will continue to focus on sharing best practices to reduce the risk of Lyme disease to Canadians.

FOCUS ON DIAGNOSTICS

The diagnosis of Lyme disease by a physician is primarily a clinical one, based on symptoms and supported by a history of possible tick exposure. Diagnosis is often made more difficult by the fact that not all patients will develop noticeable symptoms.

There are currently limitations with the available laboratory tests for Lyme disease. The stage of infection and the possible impact of treatment on the outcomes of laboratory testing should be taken into consideration during clinical diagnosis. The Canadian Public Health Laboratory Network monitors developments in laboratory diagnostics closely and publishes laboratory diagnostic guidelines that are consistent with those in the United States and Europe. Improved laboratory testing options in the future may reduce the current practice where some patients seek laboratory testing in private, for-profit laboratories that may not be using standardized testing.

Support the development of new and/or improved diagnostic tests for Lyme disease that can be performed and interpreted in a timely fashion.

Improving laboratory testing methods is important so that Lyme disease may be diagnosed at the earliest stage possible. New methods should be evaluated, and any that prove to outperform current methods will be incorporated into updated guidelines for laboratories and clinicians. Furthermore, research will need to be conducted to determine the impact of different strains of *B. burgdorferi* on diagnosis and disease in Canadians.

FOCUS ON TREATMENT

Current treatment guidelines for Lyme disease are developed by medical and scientific professional organizations, and are based on the best available evidence known worldwide. In Canada, the Association of Medical Microbiology and Infectious Diseases Canada (AMMI Canada) has endorsed and promoted the use of the Lyme disease treatment guidelines developed by the Infectious Diseases Society of America (IDSA).

Some people experience symptoms that continue more than six months following treatment. The term “Chronic Lyme Disease” has been used by some patients to describe their condition when conventional antibiotic treatments have been ineffective. Research continues into the causes of these persistent symptoms and methods of treatment since there is no definitive evidence that continuing symptoms represent an ongoing infection.

Promote data collection activities related to Lyme disease patients in Canada that can support new research on diagnostics and treatment for Lyme disease.

Developing approaches to better understand the symptoms of Lyme disease at all stages of the disease, including symptom persistence, should be considered. Potential approaches to data collection could include registries and surveys. Facilitating the dialogue between front-line health professionals and patients and their representatives will help to inform the evidence to support guideline development, and existing guidelines will be reviewed and updated in collaboration with international partners.

C. EDUCATION AND AWARENESS

Efforts need to be strengthened to enhance Lyme disease educational efforts so that they are more effective and available to Canadians and front-line health professionals.

Support the development of comprehensive educational materials for front-line health professionals to assist them in diagnosing and treating Lyme disease as early as possible, and support positive doctor-patient interactions at all stages of the Lyme disease infection.

The Canada.ca website provides information for both of these groups, including information about the causes, symptoms, risks, treatment, and prevention tips for Lyme disease. This information is reviewed and updated on a regular basis to reflect the most current validated evidence. Furthermore, each tick season, from April to October, public health authorities are engaged in delivering awareness activities to help educate the general public and front-line health professionals about Lyme disease.

Strengthening stakeholder engagement and partnerships will be critical to successful education and awareness campaigns.

Enhance existing awareness materials, and create targeted education materials for high-risk groups to reduce their risk of contracting Lyme disease through tick bites.

Existing efforts can be strengthened, as there are a number of areas requiring attention by all Lyme disease stakeholders. Assessing the current knowledge base of front-line health professionals, and developing effective and targeted educational approaches would be beneficial to help improve the recognition of Lyme disease symptoms.

VII. CONCLUSION

The Government of Canada has a national leadership role to play in the prevention and control of Lyme disease in Canada. This draft Framework outlines key areas where progress is needed. The Conference held in May 2016 has set the stage for ongoing dialogue with patients, patient groups, the medical community, scientists, researchers and governments, all of whom are committed to addressing Lyme disease in Canada

The final Framework will be published in May 2017, and will be reviewed within five years of its publication on the PHAC website.

REFERENCES

1. <http://www.healthycanadians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/lyme/index-eng.php>
2. Ogden NH Lyme disease surveillance in Canada. 2016 Presentation at Lyme meeting
3. <http://laws-lois.justice.gc.ca/eng/acts/F-7.35/FullText.html>
4. Kuehn, B.M. 2013. CDC estimates 300,000 US cases of Lyme disease annually. Journal of the American Medical Association (JAMA). 18;310(11):1110. doi: 10.1001/jama.2013.278331.
5. Rizzoli A, Hauffe H, Carpi G, Vourc H G, Neteler M, Rosa R. Lyme Borreliosis in Europe. Euro Surveill. 2011 16(27). pii: 19906