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Consultation on the Federal Framework on Lyme Disease

5%

Introductory Questions

In which Canadian province/territory do you reside?

- British Columbia
- Alberta
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- New Brunswick
- Nova Scotia
- Prince Edward Island
- Newfoundland and Labrador
- Yukon
- Northwest Territories
- Nunavut
- Outside of Canada
- Prefer not to answer

How did you become aware of this consultation?

- Received invitation from the Government of Canada
- Family, friend
- Co-worker
- Saw it on a website. Please specify:
- Other, please specify:
- Don't know
- No response

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Introductory Questions

For the purposes of this consultation, please indicate the type of group you are representing.

- Health care professional
- Complementary and alternative health care therapies
- Provincial or territorial public health authority
- Veterinarian
- Lyme disease patient
- Lyme disease patient family member
- Lyme disease patient group
- Interested Canadian
- Academia
- Government

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15%

Theme I - Surveillance

Preamble

The *Act respecting a Federal Framework on Lyme Disease* calls for the Minister of Health to "establish a national medical surveillance program for Lyme disease and use the data collected by the Agency to properly track incidence rates and the associated economic costs of Lyme disease".

Surveillance is a core public health function for the Government of Canada (Public Health Agency of Canada). Effective, timely surveillance is critical to the ability of the government and provinces/territories to accurately track health information, plan for, and respond to public health events.

The Government of Canada engages in surveillance activities to capture the number of people with Lyme disease and the locations of tick populations. It does this in partnership with provincial and territorial and local levels of government; private sector and non-governmental organizations; and health institutions and health professionals and their associations.

The Government of Canada works with these partners to undertake Lyme disease surveillance in Canada. The current surveillance system has two major components:

- The tick component includes voluntary submission of ticks found on humans and domestic animals by veterinarians and health professionals and active field surveillance.
- The human component includes national reporting of confirmed and probable Lyme disease cases by all Provinces to the Canadian Notifiable Diseases Surveillance System (including age and gender) and the collection of enhanced information from select provinces to describe a case's clinical symptoms, environmental exposure history, and additional laboratory data.

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21%

Theme I - Surveillance

Lyme disease became nationally notifiable in Canada in 2009, requiring health professionals to report the disease to their local health authority. The provincial/territorial public health authority then reports to the Government of Canada's Canadian Notifiable Diseases Surveillance System.

Are you aware that diagnosed cases of Lyme disease are nationally notifiable?

- Yes
 No

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Theme I - Surveillance

The current Lyme disease surveillance system collects information for the four purposes listed below. Please indicate which of the four purposes you have used lyme disease surveillance information in your work.

(Check all that apply)

- To track the number of cases of Lyme disease in Canada and monitor changes in the incidence rate as Lyme disease emerges
- To identify Canadian populations at risk by geographic location and by age and gender
- To describe Lyme disease symptoms in Canada to support early diagnosis and treatment
- To identify environmental risk and new geographical risk areas before human cases emerge
- Not applicable

Are there other types of Lyme disease surveillance information that you have used in your work that have not been identified?

- Yes
- No

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Theme I - Surveillance

The Public Health Agency of Canada website provides information on Lyme disease including its clinical presentation, diagnosis and surveillance. Case definitions and annual Lyme disease case counts are also provided.

Have you used this information?

- Yes
- No

The Public Health Agency of Canada also provides annual summaries of confirmed and probable cases and mapping of case locations directly to those provinces participating in enhanced surveillance activities.

Have you made use of this information?

- Yes
- No

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36%

Theme I - Surveillance

The Government of Canada released its first National Lyme Disease Surveillance report in February 2015. It provides detailed findings of national Lyme disease surveillance for the years 2009 to 2012. The Government of Canada aims to update this surveillance report on an annual basis.

Have you read the annual report?

- Yes
- No

Please use this space to provide any additional comments that would help to improve the Government of Canada Lyme disease surveillance system. (Maximum 250 words)

The Government of Canada is currently working with internal and external partners to estimate the burden of disease and associated economic costs. In order to develop these estimates, it is important to understand and assess whether and to what extent under-reporting is occurring within the surveillance system.

Would you be willing to contribute information in the future to assist the Government of Canada to assess under-reporting?

- Yes
- No

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Theme II - Guidelines and Best Practices

Preamble

Guidelines/best practices are critical to health professionals' capability to prevent, diagnose and treat Lyme disease. The *Act respecting a Federal Framework on Lyme Disease* calls for the "establishment of guidelines regarding the prevention, identification, treatment and management of Lyme disease, and the sharing of best practices throughout Canada".

For the purposes of this online consultation, the Public Health Agency of Canada establishes guidelines and best practices as follows:

- **Guidelines** are based on current, scientific evidence and best practices, and are subject to review and change as new information becomes available. The World Health Organization defines guidelines as "systematically developed evidence-based statements which assist providers, recipients and other stakeholders to make informed decisions about appropriate health interventions. Health interventions are defined broadly to include not only clinical procedures but also public health actions".
- **Best practices** are interventions, programs/services, strategies, or policies which have demonstrated changes through the use of appropriate well-documented research or evaluation methodologies. A best practice is one that is most suitable given the available evidence and particular situation or context.

Public health focuses on the entire population at both the individual and the community level. It encompasses a range of activities performed by all three levels of government (federal, provincial/territorial, and municipal) in collaboration with a wide variety of stakeholders and communities across the country.

The Government of Canada plays a leadership role in bringing health professionals together to discuss public health issues of national concern including guidelines and research. For example, the Government of Canada is responsible for the development of **national public health guidelines** for Lyme disease. These guidelines are for public health officers and health care practitioners to assist them in carrying out prevention, identification and surveillance of Lyme disease.

In partnership with provincial and territorial governments, the Government of Canada also develops **laboratory diagnostic guidelines** on Lyme disease. These guidelines assist physicians in assessing patients for Lyme disease, and help guide laboratory testing to detect Lyme disease.

Clinical or treatment guidelines on Lyme disease fall under the responsibility of the medical associations/colleges and provincial licensing authorities. The Government of Canada mobilizes these groups to update the national guidelines.

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 in various health areas including Lyme disease.

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Theme II - Guidelines and Best Practices

Please identify which of the following pertains to your work:

- Public health [i.e. surveillance, prevention]
- Medical Practice [i.e. clinical, treatment]
- Laboratory testing
- Other, please specify:

Are you aware of guidelines on Lyme disease in Canada?

- Yes
- No
- Not sure
- No response

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Theme II - Guidelines and Best Practices

The [Consensus Conference on Lyme Disease](#) document was developed in 1991 by the Government of Canada and partners and was intended to serve as a guide for those involved in the investigation and prevention of Lyme disease in Canada. The Public Health Agency of Canada is undertaking to update this document. Which key areas are consistent with your use of public health guidelines (i.e., not clinical treatment guidelines, or laboratory diagnostic guidelines).

(Check all that apply)

- Epizootiology - study of the transmission of the Lyme disease agent in wildlife
- Epidemiology - study of the patterns of infection in human populations
- Identification and Prevention of Lyme disease
- Surveillance
- Other, please identify areas:
- Unknown

With its partners on the Canadian Public Health Laboratory Network (CPHLN), the Public Health Agency of Canada is currently reviewing, and will be updating: "[The laboratory diagnosis on Lyme borreliosis: Guidelines from the Canadian Public Health Laboratory Network](#)" (2007). These guidelines have been developed to assist physicians in assessing patients for Lyme disease, and to help guide laboratory testing.

Based on your experience, are there gaps which need to be addressed in the current laboratory diagnostic guidelines?

- Yes
- No
- Not sure
- No Response

During the early stage of Lyme disease, false negative laboratory results are common.

Are you aware that the early diagnosis of Lyme disease should be based on a physician's assessment of symptoms rather than laboratory tests?

- Yes
- No

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Theme II - Guidelines and Best Practices

Which best practices on Lyme disease management, identification or prevention are you aware of and would recommend (in Canada)?

Please list them below: (Maximum 250 words)

Based on your experience, please provide the Public Health Agency of Canada with any additional feedback you have on the Lyme disease guidelines (public health and laboratory diagnostics) and/or best practices. (Maximum 250 words)

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Theme III - Standardized Educational Materials/Increased Public Health Care Provider Awareness

Preamble

The *Act respecting a Federal Framework on Lyme Disease* calls for "the creation and distribution of standardized educational materials related to Lyme disease, for use by any public health care providers within Canada, designed to increase national awareness about the disease and enhance its prevention, identification, treatment and management".

As per the Public Health Agency's Action Plan on Lyme Disease, the Agency works closely with provincial and territorial governments and other partners to educate and raise awareness of Lyme disease among the general public and health professionals so that Canadians can better protect themselves against this infectious disease. Activities include:

- Sharing information on how Canadians can protect themselves;
- Collaborating with family practitioners to enhance their knowledge and capacity for prompt diagnosis and treatment; and
- Developing information for public health professionals on surveillance, prevention and control.

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Theme III - Standardized Educational Materials/Increased Public Health Care Provider Awareness

In your experience, is Lyme disease and related tick borne illnesses a clinical concern in your province/territory?

- Yes
- No
- Not sure
- No response

Have you seen material (online, social media, posters, brochures etc.) on Lyme disease in Canada?

- Yes
- No
- Not sure
- No response

Please indicate if you have participated in/seen any of the following Public Health Agency of Canada Lyme disease awareness products/activities:

(Check all that apply)

- Public Health Agency of Canada's webinar(s) on Lyme Disease
- Advertisements in medical journals
- Presentations at national and international conferences
- Articles in medical journals
- Web banners or advertisements on the Weather Network channel or on-line site
- Social media postings targeted at health professionals
- Lyme disease webpage for health professionals on the Public Health Agency Canada's website
- Did not participate/see material

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Theme III - Standardized Educational Materials/Increased Public Health Care Provider Awareness

The Government of Canada uses multiple formats to reach health professionals and Canadians about Lyme disease, including Social Media (Facebook, Twitter), articles in local and national newspapers and magazines, the Public Health Agency of Canada's web site, partnerships with provinces and territories to communicate across the country, advertisements on the Weather Network, Webinars, Conference presentations, etc.

Please check all of the formats you/your organization have used to learn about Lyme disease and check all of the reasons why you used that format.

(Check all that apply)

	Credible source	Relevant	Easy to access	Evidence based information	Reflects emerging science
Symposia/Conferences	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online information from community-based/non-governmental organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online information from provincial/territorial government agencies (e.g. Ministry of Health) or local health authorities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online information from Government of Canada	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Academic journals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online courses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practicum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peer-reviewed articles or literature reviews	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Workshops/small group learning sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Canadian Institute for Health Information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
International organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please list any other formats you/your organization have used for information on Lyme disease and the reasons why. (Maximum



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Theme III - Standardized Educational Materials/Increased Public Health Care Provider Awareness


Are you aware of any Lyme disease educational materials or tools tailored to health professionals in Canada?

- Yes
- No
- Not sure/No response

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Theme III - Standardized Educational Materials/Increased Public Health Care Provider Awareness

Has your organization collaborated in the past with other organizations to develop educational materials/ training/tools for health professionals on Lyme disease?

Yes

No

Does your organization disseminate information/tools about Lyme disease and its prevention to health professionals?

Yes

No

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Thank you for taking the time to provide valuable input to support the Government of Canada in the development of the Federal Framework on Lyme Disease.

Should you have any additional comments on this online consultation, please send them to the following email address: maladie_lyme_disease@phac-aspc.gc.ca by June 30, 2015, and indicate "Consultation" in the subject line.

If there are any changes you would like to make to your responses, please do so now before you click the "Submit" button below.

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