2015 ONLINE CONSULTATION:

FEEDBACK FROM CANADIANS TO IMPROVE THE FEDERAL FRAMEWORK ON LYME DISEASE

PROTECTING AND EMPOWERING CANADIANS TO IMPROVE THEIR HEALTH

Public Health Agency of Canada
Agence de la santé publique du Canada

Canada

TO PROMOTE AND PROTECT THE HEALTH OF CANADIANS THROUGH LEADERSHIP, PARTNERSHIP, INNOVATION AND ACTION IN PUBLIC HEALTH.
—Public Health Agency of Canada

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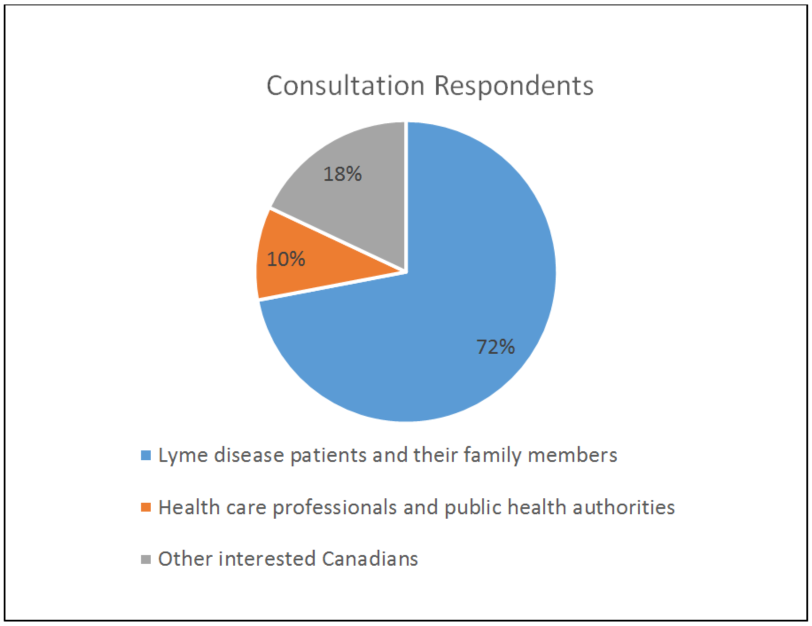
1 INTRODUCTION

The *Act respecting a Federal Framework on Lyme Disease* came into force on December 16, 2014. Under this legislation, the Minister of Health was required to convene a conference with the provincial and territorial ministers and stakeholders, including representatives of the medical community and patients' groups, for the purpose of developing a comprehensive federal framework that includes:

- 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;
- the establishment of **guidelines** regarding the prevention, identification, treatment and management of Lyme disease, and the sharing of **best practices** throughout Canada; and
- 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 prevention, identification, treatment and management.

To inform the development of the Framework with the input of Canadians, an online qualitative consultation was held by the Public Health Agency of Canada from June 1 to June 30, 2015. More than 1,000 respondents participated, including: Lyme disease patients and their family members (72%); health care professionals and public health authorities (10%); and other interested Canadians (18%).



This document presents an overview of the feedback received during the consultation, which informed the structure and organization of the conference that took place in Ottawa from May 15-17, 2016.

This Report was prepared for information purposes only, to summarize the feedback from Canadians who participated in the online consultation. The key messages and ideas summarized in this report are not intended to indicate a consensus of opinion or agreement across respondent groups on these topics. The opinions and views expressed through the consultation are those of the respondents and do not necessarily reflect the opinions and views of the Government of Canada.

2 SURVEILLANCE

To improve the **National Medical Surveillance Program for Lyme Disease**, consultation respondents suggested:

- Making the national Lyme disease surveillance system publicly accessible and interactive by publishing it on social media and using better tags to make it easier to find in an online search.
- Developing a standard tick reporting procedure that is proactive and systematic, and explains how information is collected.
- Making active and timely tick surveillance mandatory in each province/municipality.
- Providing education to improve physician understanding of the reporting process and conducting occasional surveys to ensure front-line doctors are being vigilant.
- Incorporating data from veterinarians, naturopathic physicians and out-of-country practitioners; especially physicians in the United States who have diagnosed and/or treated Canadian patients.
- Capturing additional information in the system, such as ‘suspicious or probable’ Lyme disease cases that may not meet restrictive surveillance standards (e.g., clinical diagnosis cases, etc.), late-stage Lyme disease cases (e.g., patients who were misdiagnosed) and those infected *in utero* or through sexual transmission.
- Improving the surveillance of tick prevalence in vertebrate hosts, such as deer, dogs, rodents and migratory birds.
- Conducting tick surveillance more often during the times of the year ticks are more active and doing more tick drags in public places such as golf courses, parks, and beaches.
- Asking veterinarians to submit ticks for testing without charging a fee.
- Considering other tick species for surveillance and checking for tick-borne infections other than *Borrelia*.

3 GUIDELINES

To improve **Guidelines for the Prevention, Identification, Treatment and Management of Lyme Disease**, consultation respondents suggested:

- Including more stakeholders when revising guidelines, such as: patients and their family members; health care professionals with experience diagnosing and treating Lyme disease and co-infections; and Lyme disease researchers.
- Ensuring guidelines cover late-stage and chronic Lyme disease (as well as co-infections), the duration of antibiotic therapy and other treatment and diagnosis options.
- Investing in research to develop ‘made in Canada’ guidelines and best practices, and reflecting current research from microbiologists and Lyme disease patients.
- Updating guidelines on where Lyme disease can be contracted and addressing how to help Canadian patients who have been diagnosed, and are being treated, outside of Canada.
- Making European guidelines accessible when physicians need to deal with imported cases.

Respondents also had specific recommendations to improve:

1. PREVENTION AND IDENTIFICATION GUIDELINES

- Emphasize the importance of treatment based on a clinical diagnosis, rather than waiting for test results.
- Include a list of ways to prevent tick bites, safely remove ticks, and address co-infections.

2. LABORATORY DIAGNOSTIC (TESTING) GUIDELINES

- Upgrade the laboratory testing program so it uses a detection threshold with the right sensitivity to catch infections and reduce false negatives.
- Enable patients with negative ELISA results, but with clinical symptoms, to have access to Western Blot or end the two-tiered testing system.
- Ensure common strains of the bacteria are tested as well as the presence of spirochetes. Take into account the diversity of the *Borrelia* bacteria and in looking at banding results.
- Research better testing that would allow for earlier diagnosis and identify Lyme disease in its early stages, in post-treatment syndrome, and/or when it becomes a chronic disease.
- Investigate newer diagnostic testing strategies that reflect current research and thinking, as well as testing done in other countries.
- Be clear about the timing of serology: when it should be done; how long the results may take from the National Microbiology Laboratory; and the rates of positives and negatives.
- Provide guidance to physicians about what they should consider testing for when symptoms persist but Lyme tests are negative, what they should do when there is no bull’s eye rash or flu-like symptoms, and what they should do when presented with positive tests from American labs using unapproved protocols.

3. TREATMENT AND MANAGEMENT GUIDELINES

- Address acute and chronic conditions and consider various age and gender groups.
- Allow for continued treatment until after symptoms are gone.
- Consider research studies conducted to determine which drugs or drug combinations should be used to eradicate Lyme disease.
- Further investigate treatment methods; especially for persistent forms of Lyme disease and late-stage Lyme disease.
- Allow physicians to prescribe long-term antibiotic treatment or collect evidence to show the disadvantages of prolonged antibiotic treatment and the dangers of intravenous antibiotics.

4 BEST PRACTICES

To improve **Best Practices**, consultation respondents suggested:

- Keeping guidelines science- and evidence-based by avoiding anecdotal and unsupported evidence of Lyme disease infection and transmission.
- Encouraging doctors and other health care practitioners experienced in diagnosing and treating Lyme disease to share information with their colleagues and medical associations.
- Ensuring accuracy and specificity in diagnosis, broader and more accurate testing, and multiple methods of treatment (not just antibiotics).
- Standardizing testing and treatment guidelines so that clinical assessment overrides negative testing in suspicious cases.
- Educating doctors and infectious disease specialists about Lyme disease and the importance of clinical diagnosis, prompt treatment, and treatment for the right length of time.
- Ensuring all ticks found on humans and companion animals are sent to labs for testing.
- Providing more information to veterinarians and having more preventative drugs for dogs to kill ticks before they have a chance to transmit the disease.
- Using best practices and resources.
- Regularly updating physicians about changing provincial, national and international risk areas and/or temporal risk areas.
- Working with the Canadian Lyme Disease Foundation and other organizations, as well as with American Lyme doctor specialists who are treating Canadian patients.

5 AWARENESS

To improve **Public and Public Health Care Provider Awareness** about Lyme disease, consultation respondents suggested:

- Making new and existing information easier to find by:
    - Advertising using public service announcements on television and radio stations, in newspapers and magazines, on websites, and through social media.
    - Posting signs on trail markers in parks, campsites and other recreational areas, such as golf courses. Information could also be available at campsite or hiking registration areas.
    - Putting posters up and having flyers, brochures, and other information available at doctor's offices, pharmacies, emergency waiting areas, hospitals, walk-in clinics, veterinarian clinics, and any other place where a person may go for treatment for themselves, a family member or a pet.
    - Providing information to outdoor gear and clothing retail stores, and at gas stations and hotel resorts in high-risk areas.
    - Posting billboards and setting up kiosks at school or community events, as well as ensuring that Service Canada kiosks feature the information.
    - Providing information to schools and libraries for awareness and educational purposes, as well as municipal and community centers and public health centers.
- Ensuring information will help people identify ticks and the geographic areas where they are endemic, and informing people on how to protect themselves.
- Providing a list of Canadian resources on who will diagnose, test, and treat in all provinces and territories, with contact information.
- Identify susceptible populations and at-risk professions in order to direct protective behaviours.
- Creating a dedicated, national Lyme website with links to all produced, collected and coordinated information.
- Conducting nationally coordinated public awareness, social marketing and/or public health campaigns with the participation of all provinces, territories and municipalities. Campaigns could be run each May during Lyme disease awareness month and again in autumn.
- Making existing information easier to read, up-to-date, and accurate; including warnings about non-approved testing and treatments; and including information on early- and late-stage Lyme disease.

6 CONCLUSION

The Government of Canada thanks all Canadians who took the time to provide feedback and share their personal experiences on this important public health matter.

The Public Health Agency of Canada has been working to develop the Federal Framework on Lyme disease including holding the Federal Framework on Lyme disease Conference, May 15-17, 2016. You may wish to follow this important initiative, as well as review the conference summary report, at the following link: https://www.canada.ca/en/public-health/services/diseases/lyme-disease/federal-framework-lyme-disease-conference.html