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## Case 12 : Policy Window - When Lyme is in the Limelight

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## CASE 12

### Policy Window – When Lyme is in the Limelight

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It was a bright sunny morning, which was recently an unusual sight for Ottawa, Ontario. Melissa Doug, a senior policy analyst at the Centre for Food-Borne, Environmental and Zoonotic Infectious Diseases (CFEZID), was on duty to prepare Question Period (QP) notes. The CFEZID, which is part of the Infectious Disease Prevention and Control Branch at the Public Health Agency of Canada (PHAC), was where Melissa started as a policy analyst almost seven years ago. After waking up at 7:30 in the morning, she reached for her phone and was not surprised to see a request to prepare a QP note for the Minister of Health. The QP note was to contain an update on the status of the activities being undertaken for the *Action Plan on Lyme Disease* (PHAC, 2017). The request was triggered by the recent media attention on the alarming rise of Lyme disease cases in Nova Scotia. Melissa was aiming to have the Director's approval by 8:30 a.m. so the QP note with information about current statistics on Lyme disease cases in Canada could be forwarded to the Minister of Health for the upcoming roundtable discussion.

#### **BACKGROUND: LYME DISEASE IN CANADA**

Lyme disease is an emerging, vector-borne infectious disease in Canada and is caused by the bacterium *Borrelia burgdorferi*. This bacterium is transmitted to people through the bite of an infected tick. There are approximately 40 species of ticks in Canada (CFEZID, 2017), but only some of them transmit the pathogens causing human illness. *B. burgdorferi* is exclusively transmitted by blacklegged ticks (also called deer ticks) and western blacklegged ticks (CFEZID, 2017). Lyme disease is the most common tick-borne illness in Canada, and the risk of contracting Lyme disease exists in southern parts of British Columbia and Manitoba, Southern and Eastern Ontario, Southern Quebec, New Brunswick, and some areas in Nova Scotia (Ogden, Koffi, Pelcat, & Lindsay, 2014). In 2018, the PHAC released a map of Lyme disease risk areas in Canada (Exhibit 1). The geographical distribution of Lyme disease risk is expanding because of warming weather, and the consequent geographical invasion of alternate host animals such as migratory birds and dusky-footed wood rats carrying ticks (Ogden et al., 2014).

People engaging in outdoor activities in affected forested areas for either occupational or leisure activities such as camping, hiking, gardening, golfing, dog walking, hunting, fishing, or simply sitting outdoors or near compost piles, are at a higher risk of acquiring the disease from tick bites (CFEZID, 2017).

Lyme disease became nationally notifiable in 2009 to allow the authorities to monitor and control the rising incidence of the disease. About 144 cases were reported that year and were estimated to have been underreported because of insufficient awareness about the disease among frontline clinicians. Since then, the number of newly diagnosed cases has been steadily

increasing and almost 1,000 Canadians were diagnosed with Lyme disease in 2016 (CFEZID, 2017). The rise in the number of Lyme disease cases reported may be attributed to the implementation of a new surveillance system, as well as the advancement in disease knowledge and diagnostic procedures. However, there is still some likelihood that cases are underreported because of gaps in both the surveillance system and the reporting system (CFEZID, 2017). Nova Scotia reported the highest incidence of Lyme disease in Canada in 2016 at 34.4 per 100,000 people, which is 12.7 times the national average (PHAC, 2018b).

### **EVOLUTION OF THE FEDERAL RESPONSE ON LYME DISEASE—THE CHALLENGE**

Lyme disease poses a rapidly evolving challenge for public health professionals and frontline clinicians. Inconsistencies in clinical practices, such as variable diagnostic approaches (clinical diagnosis versus laboratory diagnosis), variable treatment protocols (post-exposure antibiotic prophylaxis versus symptomatic treatment), and controversies surrounding the reliability of laboratory testing technology necessitate that the best practice guidelines for Lyme disease be developed at the national level (CFEZID, 2017). Tick bites may go unnoticed because of the extremely small size of the ticks and the painless nature of the bite. This may result in a delayed or inaccurate diagnosis and potential for illness to become severe, which makes primary prevention even more important. Capturing the exact number of people with Lyme disease by compiling data collected from provincial and territorial public health authorities is another challenging aspect of Lyme disease surveillance because of the discrepancies in data on travel-acquired cases and the dynamic and varying provincial disease reporting systems (PHAC, 2018b).

These challenges, along with the emerging nature of Lyme disease and its link to climate change, led to a unified public health response to Lyme disease in the form of a federal framework. The *Federal Framework on Lyme Disease Act* was assented in 2014 and mandated the Minister of Health to organize a conference to develop the federal response on tackling Lyme disease (Federal Framework on Lyme Disease Act, 2014). Six months later, the Canadian Institutes of Health Research, in collaboration with the PHAC, organized a Best Brains Exchange<sup>1</sup> (Canadian Institutes of Health Research, 2016). This meeting provided an opportunity to exchange and brainstorm ideas for effective and evidence-based diagnostic and treatment protocols for Lyme disease. Participants included national and international experts, including policy-makers, researchers, and other key stakeholders. In May 2016, the PHAC, on behalf of the Minister of Health, organized a national conference to inform and guide policy direction on Lyme disease (PHAC, 2017). Representatives from health care provider associations, all levels of government, academia, patients, and advocacy groups participated in the conference and provided feedback on the draft federal framework on Lyme disease.

The final version of the framework was published in May 2017. It outlines three key pillars for the federal public health response in the areas of adequate prevention, early diagnosis, and timely treatment of Lyme disease. The three pillars—surveillance, education and awareness, and guidelines and best practices—lay the foundation for the PHAC *Action Plan on Lyme Disease* (PHAC, 2017).

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<sup>1</sup> *Best Brains Exchanges* are one-day, in-camera gatherings for policy makers, researchers, and field specialists with expertise on a topic that has been recognized as a high priority by provincial/territorial ministries of health and the Health Portfolio (the Canadian Food Inspection Agency, the Canadian Institutes of Health Research, Health Canada, the Patented Medicine Prices Review Board, and the PHAC) in order to support and facilitate the exchange and use of information for mutual learning and benefit (Canadian Institutes of Health Research, 2018).

### FEDERAL FRAMEWORK ON LYME DISEASE—ENGAGEMENT STRATEGY

A comprehensive approach to Lyme disease prevention and control requires multidisciplinary collaboration with relevant stakeholders and partners. Stakeholders hold a diverse range of concerns and perspectives regarding the prevention, diagnosis, treatment, and control of Lyme disease. They are also concerned with the usefulness, consistency, and comprehensiveness of the information available to public health and primary health care practitioners, as well as the general population, on the topic of Lyme disease.

Melissa is a part of the Lyme Disease Working Group at the PHAC. Melissa and her team have prepared an engagement strategy to facilitate the implementation of the *Action Plan on Lyme Disease* (PHAC, 2018c). The Lyme Disease Working Group consists of policy analysts, a technical lead on epidemiology, and a Health Professional Task Force, and it is divided into a policy arm and a health professional arm. The policy analysts synthesize evidence into policy and keep the rest of the department informed on all policy aspects related to Lyme disease. The technical lead supports the team by tracking and keeping the group updated on surveillance activities. The health care professional task force consists of medical advisors and nurse consultants who positively influence evidence-based decision making, provide insight into best practices and guidelines, and synthesize educational and health promotional material for primary care practitioners. The policy analysts and the health professional groups hold biweekly meetings to collaborate as needed, to debrief the department about *Action Plan on Lyme Disease* activities, and to ensure that their work is progressing and is mutually inclusive.

The engagement strategy also aims to encourage information sharing, knowledge translation, and partnership building to establish a mutually beneficial relationship between the Government of Canada and various Lyme disease stakeholders (PHAC, 2018c). Building coalitions and engaging stakeholders are central to achieving effective outcomes in terms of the three pillars of the Action Plan. Working collaboratively with partners and stakeholders to improve educational and awareness tools will enrich existing prevention and control efforts. The engagement activities also enable stakeholders to share their expertise and personal experience to devise innovative methods for surveillance and control (PHAC, 2018c). Feedback received from various stakeholders about knowledge available to public health practitioners, physicians, and the public about Lyme disease helps to identify the gaps in public health response and research (PHAC, 2018c).

Stakeholder engagement is crucial at each step of the Action Plan, from planning to implementation and then to evaluation. A multipronged approach is required to address the needs and interests of different participants (Mitton, Smith, Peacock, Evoy, & Abelson, 2009). For example, requests for feedback on the documents can be combined with technical workshops depending on the expertise, experience, or interest of the audience. Audience segmentation can guide the right approach and the appropriate platform for developing and exercising engagement activities. Keeping in mind their level of technical expertise and busy schedules, health care professionals may benefit more from technical webinars and workshops. Conversely, online consultation tools might benefit individuals with a general interest and investment in Lyme disease. Potential platforms useful for engagement activities include email notifications, government websites, social media channels, and bilateral meetings.

### STAKEHOLDERS

The engagement strategy aims to identify and attract a broad range of interested partners who have diverse areas of expertise, knowledge, and viewpoints. Potential stakeholders include public health practitioners at all levels of government (municipal, provincial/territorial, and federal), academia, researchers, health care professionals, professional associations,

nongovernment organizations, advocacy groups, patients and their caregivers, at-risk populations, the media, and the general public (PHAC, 2018c).

Identification and acknowledgement of various influential groups' perspectives is followed by interacting and managing the stakeholders in an appropriate way (Brugha & Varvasovszky, 2000). Analyzing various characteristics of the stakeholder groups such as level of interest and commitment, level of influence, public perception, supporting or opposing positions, priorities, sources of funding, and conflicts of interest is one method of managing the wide variety of groups involved (Brugha & Varvasovszky, 2000). The management of stakeholders and the implementation of the Action Plan run in a positive feedback loop, where better engagement of the stakeholders improves the implementation process, which in turn attracts more stakeholders important to program implementation.

### **1. Federal Government**

The Minister of Health is responsible for protecting and promoting the health of Canadians, and this role is supported by the Health Portfolio (Health Canada, 2017). The Health Portfolio comprises Health Canada, the PHAC, the Canadian Institutes of Health Research, the Patented Medicine Prices Review Board, and the Canadian Food Inspection Agency. The PHAC is the federal lead in mobilizing pan-Canadian action to maintain and improve public health, and to prevent disease through building and sustaining a public health network in an open, transparent, and relevant fashion (Health Canada, 2017).

### **2. Provincial Governments**

The Ontario Ministry of Health and Long-Term Care, Manitoba Health, the Saskatchewan Ministry of Health, the New Brunswick Department of Health, and the Institut National de Santé Publique du Québec are the provincial actors who have an important role in policy decisions regarding the prevention and control of Lyme disease in their respective provinces (PHAC, 2018c). These actors have set up visions, goals, objectives, and standards in order to play their respective roles using a collaborative public health response and coordinated care approach in their communities.

### **3. Health Professionals**

The Canadian Medical Association is the professional association of Canadian physicians, uniting more than 85,000 members on health and medical matters. The Association's rich history of advocacy for evidence-based practice led to some of Canada's most important health policy modifications (Canadian Medical Association, n.d.). The Association of Medical Microbiology and Infectious Disease Canada (AMMI Canada) represents physicians, clinical microbiologists, and researchers from microbiology and infectious diseases fields. AMMI Canada aims to serve the public through education, research, and clinical practice (AMMI Canada, 2018). The College of Family Physicians of Canada regulates family physicians and establishes standards for their training, certification, and professional development (The College of Family Physicians of Canada, n.d.). Infection Prevention and Control Canada is a multidisciplinary association committed to the well-being and safety of Canadians by educating, standardizing, and advocating for infection control and prevention strategies (Infection Prevention and Control Canada, 2018). These health professional organizations operate at the national level and their representation in the engagement strategy will strengthen the Canada-wide policy perspective.

### **4. Academia and Research**

Queen's University, Mount Allison University, Bishop's University, the G. Magnotta Foundation, and Lakehead University are some Canadian institutes located in Lyme

disease-affected provinces. These institutes are also involved in the engagement process in order to contribute the most current knowledge and evidence-based methods and practices.

### 5. Patient Groups

LymeHope, Voices of Canadians about Lyme (VOCAL), and the Canadian Lyme Disease Foundation (CanLyme) are some of the patient advocacy groups at the national level. Provincial Lyme disease associations include Manitoba Lyme Disease, Lyme Ontario, the Lyme Disease Association of Alberta, the Saskatchewan Lyme Disease Association, and the Nova Scotia Lyme Disease Support Group. These patient advocacy groups have been at the forefront of pushing the government's response to Lyme disease in Canada (PHAC, 2018c). They advocate for patients to be equal partners in Lyme disease policy development and push to standardize educational material for health care providers.

### WHAT CAN THEY BRING?

Stakeholders bring various perspectives, expertise, and opinions. Valuing these viewpoints and integrating these competencies can produce the most coordinated and holistic response to Lyme disease (PHAC, 2018c). Researchers, for example, can contribute by providing the most up-to-date knowledge and scientific evidence. Health care professionals can provide valuable insight into effective clinical methods, highlight gaps in current best practices, and iterate challenges related to clinical diagnoses and treatment. Representatives from Indigenous populations can identify the impact of increasing incidence of Lyme disease on their cultural practices. At-risk and vulnerable populations require a more tailored approach for effective health protection and promotion awareness and activities. The employees of governmental organizations, such as Parks Canada, can highlight the hardships of maintaining health promotion and protection protocols in daily work-related activities. For example, employees may not be able to wear long-sleeved shirts and light-coloured clothing because of extreme heat or dress code requirements. Patients, families, and their caregivers can bring their personal and lived experiences in challenges of diagnosis, treatment, and recovery.

### ROUNDTABLE DISCUSSION

Melissa thought about all the engagement activities undertaken so far to refine and guide the implementation of the *Action Plan on Lyme Disease* and updated the summary of recent activities in her QP note. She also included an update about the upcoming roundtable meeting with stakeholders as part of the engagement strategy. The roundtable discussion is one of the major coalition activities planned as part of the strategy, involving many of the stakeholders and partner groups. She has been preparing for this discussion with her manager and colleagues for the past six weeks. She understands that Lyme disease is not only an emerging public health concern, but that it is also a politically charged topic because of the ideological differences various stakeholders have regarding possible solutions for this problem. Patients' perspectives on missed Lyme disease diagnosis and lack of universal guidelines for diagnosis and treatment make it a particularly sensitive topic for many groups. The political nature of Lyme disease and sensitivity attached to this topic make it a controversial subject. Disapproval of the term *chronic Lyme disease* in medical literature and the recommendation against long term antibiotic treatment add to the controversy (R. Ahmed, personal communication, 2018). Because of these factors, Melissa is skeptical about the end results of the roundtable discussion.

The roundtable discussion will be an all-day event held in Ottawa. A large U-shaped table will be set up to let everyone listen to information and opinions firsthand and to foster new partnerships among participants. An external professional facilitator has been hired to facilitate the discussion and minimize bias in proposing concrete actionable items and identifying future roles and responsibilities. In the spirit of openness and transparency, the final list of attendees and their affiliations has been shared with all who will attend. The roundtable discussion will be



conducted in both official languages to ensure full participation from all attendees. Melissa and her team understand the importance of performing a detailed stakeholder analysis to facilitate the implementation of the Action Plan and discern the policy context. They have also prepared a logic model to appraise the feasibility of future directions of policy making. The team is aware of the theories of policy development and their implication on future modifications in forming Lyme disease policy.

### WHY ROUNDTABLE?

The *Federal Framework on Lyme Disease Act* mandates the preparation and implementation of the Action Plan and the engagement of relevant stakeholders. The roundtable discussion is an important activity in the engagement strategy because it will not only bring a diverse group of partners together to have an open dialogue, but it will also help obtain a broad range of values and perspectives on the three pillars of the framework (Exhibit 2). A roundtable discussion is an excellent opportunity to explore answers to some crucial questions, including: What are the possible ways to expand data collection methods to include people who do not fit the classic case definition? What roles and responsibilities can be delegated to various stakeholders in order to advance collaborative work on Lyme disease? Which health care professionals should be targeted for best practices guidelines preparation? What should the public awareness campaign focus on? And what should the Lyme disease research network, which was recently granted \$4 million to expand its research, prioritize? Although the long-term outcome of the engagement strategy is to protect Canadians from potential health risks associated with Lyme disease, the immediate outcome of the activities will determine the timeline and strategy for achieving this long-term outcome.

The Health Professional Task Force at the PHAC invited potentially interested stakeholders to participate in the discussion. The team is hoping to have strong representation from all sectors at the national level to identify opportunities for collaboration and to continue to advance work on Lyme disease. Most of the organizations have accepted the invitations; others have decided to send a delegate to represent the organization; and a few have declined, stating that Lyme disease is not a priority task for them at the moment (Exhibit 3). It is critical to have a strong voice supporting the incorporation of evidence-based research into the unified federal response, and to be able to successfully achieve positive long-term outcomes for the Lyme disease strategy.

### CONTROVERSY

Lyme disease is a politically charged topic. The Government of Canada emphasizes developing a national surveillance program, best practice guidelines, and standard educational materials to increase Canadians' awareness about Lyme disease by exclusively using scientifically proven and evidence-informed methods and practices. Some of the Lyme disease advocacy groups have been at the forefront to push the federal response toward implementing a Lyme disease care model similar to the American model, which is based on partially validated methods of diagnosis and treatment. These patient groups advocate for patients to be considered equal partners in decision-making at the policy level. Although patients' perspectives are critical to understanding the gaps related to diagnosis, treatment, and recovery, their experiences must be balanced with evidence-based information and expert opinion. There are many conflicts of ideology between patient advocacy groups and technical experts, which is why successful implementation of the roundtable discussion is critical for a smooth advancement of the Action Plan.

Melissa finished her QP note and sent it to the Director so it could be approved and forwarded to the Minister's office via the single window of the Infectious Disease Prevention and Control Branch. It was now 8:30 a.m. and she rolled out of bed and peeked inside her mother's room.

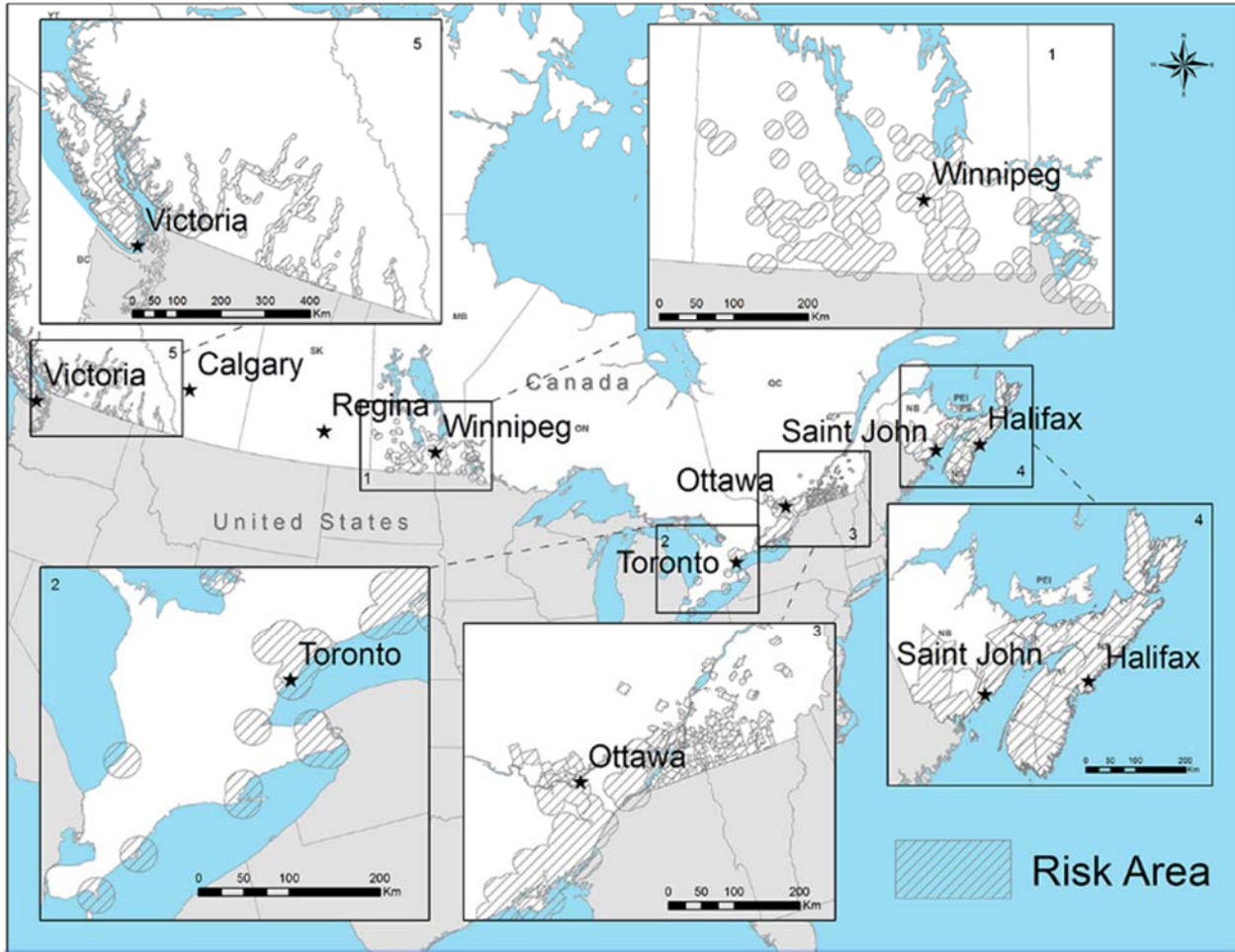
Her mother has suffered from arthritis for the past nine years. She was initially labelled as a 'suspected case of Lyme' but laboratory testing did not provide a formal diagnosis. Looking at the clock again, Melissa gets ready to go to the PHAC office at 130 Colonnade Road. On her drive, she thinks about her journey with Lyme disease so far and the uncertainties about the outcomes of the roundtable discussion.

### CONCLUSION

Melissa has seen the *Action Plan on Lyme Disease* pass through evolutionary steps. As a very sensitive issue for a lot of people (for her also because of her mother's condition), Lyme disease brings out many controversies and concerns among all stakeholders. Having an open dialogue to establish clear-cut responsibilities and expectations is the key to a successful implementation of the Action Plan. While going up the stairs, she thinks about the logistics and operations of the roundtable discussion and keeps asking the following questions: What will happen at the roundtable discussion? Who will represent the different organizations? Will the representatives be able to truly represent their organizational perspectives? Will they be able to stand by the evidence-based research approach? Will they be able to dissociate their personal experiences with Lyme disease diagnoses from their professional opinions? Will they be able to control their tone and tailor their messages according to the audience? Will this roundtable be able to advance the Action Plan further or push it back? Four years' worth of her team's time, energy, and efforts depend on the outcomes of this roundtable discussion.

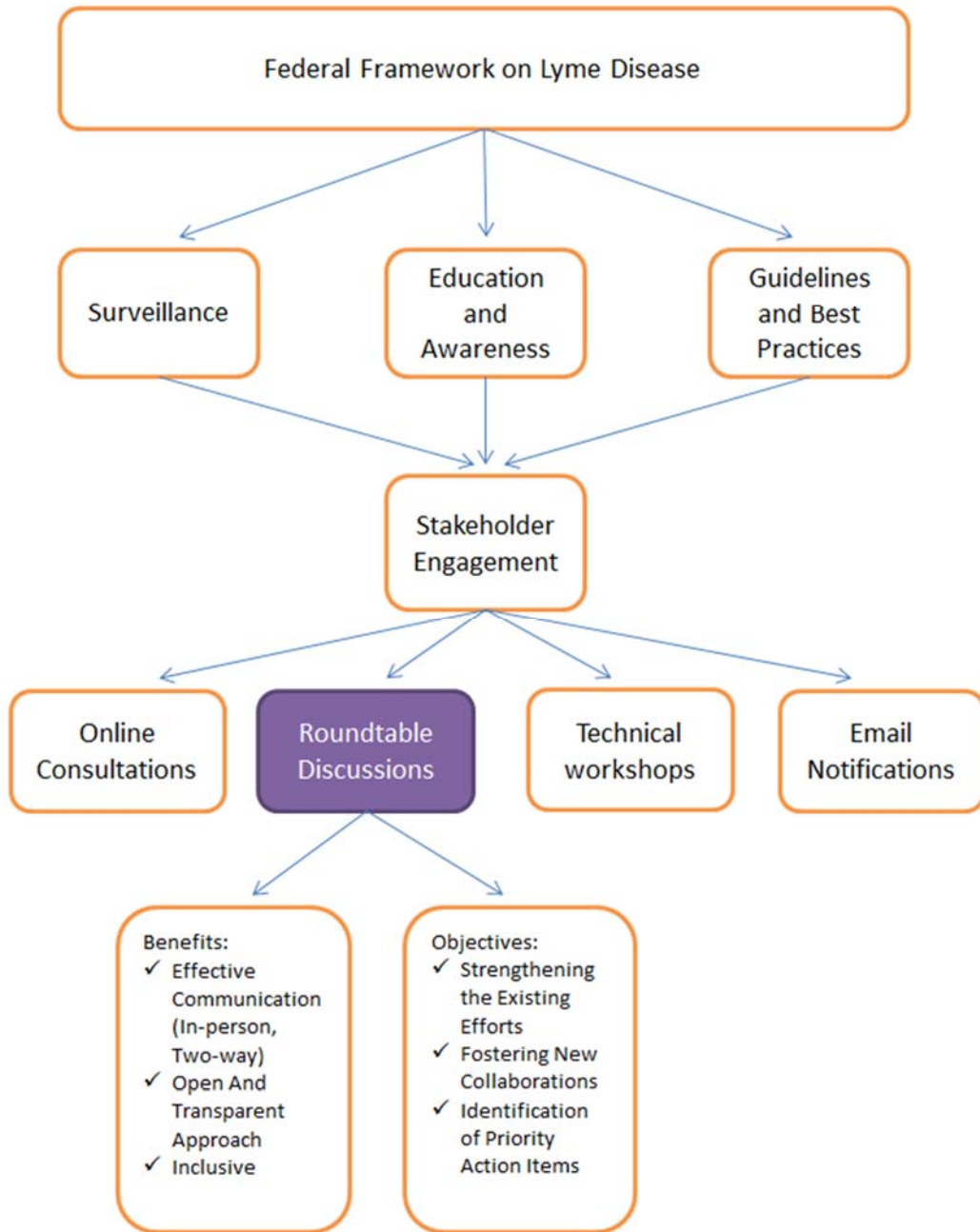


**EXHIBIT 1**  
**Five Locations Where Tick Bite and Lyme Disease Risks Are Known**



Source: Public Health Agency of Canada, 2018a.

EXHIBIT 2



Source: Created by Author, derived from Public Health Agency of Canada, 2018.

### EXHIBIT 3

#### List of Stakeholder Organizations (Accepted Invitation)

##### Federal Government

- Public Health Agency of Canada

##### Provincial Government

- New Brunswick Department of Health
- Ontario Ministry of Health and Long-Term Care
- Institut national de santé publique du Québec
- Manitoba Health
- Saskatchewan Ministry of Health

##### Health Professionals

- Indigenous Physicians Association of Canada
- Association of Medical Microbiology and Infectious Disease Canada
- Canadian Association of Naturopathic Doctors
- Canadian Association of Schools of Nursing
- Centre for Effective Practice
- College of Family Physicians of Canada
- Medical Prof. Corp.
- Naturopathic Family Medicine Inc.
- Society of Obstetricians and Gynecologists of Canada
- Canadian Veterinary Medical Association

##### Patient Groups

- LymeHope
- CanLyme
- Voices of Canadians About Lyme (VOCAL)
- Nova Scotia Lyme Disease Support Group
- Manitoba Lyme Disease
- LymeNB
- Ontario Lyme Alliance
- Lyme Ontario
- Lyme Disease Association of Alberta
- Saskatchewan Lyme Disease Association

##### Academia/Research

- Queen's University
- G. Magnotta Lyme Disease Research Lab (University of Guelph)
- G. Magnotta Foundation

#### List of Stakeholder Organizations (Regrets)

- Canadian Medical Association
- Ministère de la Santé et des Services sociaux
- Association québécoise de la maladie de Lyme
- Bishop's University
- Infection Prevention and Control Canada
- Mount Allison University
- Canadian Nurses Association
- Canadian Paediatric Society
- Lakehead University

Source: Public Health Agency of Canada, 2018c.

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## INSTRUCTOR GUIDANCE

### Policy Window – When Lyme is in the Limelight

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*Amardeep Thind, MD, PhD (Professor, Western University)*

#### BACKGROUND

Melissa Doug is a senior policy analyst at the Centre for Food-Borne, Environmental and Zoonotic Infectious Diseases at the Public Health Agency of Canada. She has been tasked with preparing Question Period (QP) notes for the Minister of Health. She has very little time to prepare a clear, succinct, and jargon-free note by 8:30 a.m. for the Director's approval. Once the note is approved, the Director will forward it to the Minister of Health with an update on the status of activities being undertaken for the *Action Plan on Lyme Disease*. The QP note also includes an update on the upcoming roundtable discussion with stakeholders as part of the Lyme disease engagement strategy. Melissa has been working on Lyme disease policy for more than four years and her team's energy and efforts will come to fruition during this roundtable discussion.

Lyme disease is a rapidly growing public health challenge in Canada. The absence of a consolidated national response to Lyme disease led to the *Federal Framework on Lyme Disease Act*, which mandated the Minister of Health to call a national conference on the issue. The Public Health Agency of Canada developed the federal *Action Plan on Lyme Disease* on behalf of the Minister of Health. The Action Plan is based on three pillars—surveillance, education and awareness, and guidelines and best practices. Developing the plan requires comprehensive consultation with all stakeholder groups to ensure that diverse perspectives in policy development and implementation are incorporated. Stakeholder engagement in the implementation process is key to addressing the specific needs of at-risk groups and narrowing the gaps in current practices at the policy level.

The purpose of this case is to underscore the importance of stakeholder analysis and management in defining future policy directions and successful program implementation. Incorporating the real-world perspectives of diverse stakeholders is an essential component of an effective policy-making process.

#### OBJECTIVES

1. Develop strategies for stakeholder identification to inform population-based policies.
2. Analyze the significance of various stakeholder analysis techniques in order to address emerging public health issues.
3. Construct a map of relevant stakeholders on an interest–influence matrix for a structured approach to stakeholder analysis.
4. Practice compiling evidence to synthesize policy brief communication with imperfect and incomplete information regarding emerging infectious diseases.
5. Appraise the value of building partnerships to advocate for evidence-informed policies.

### DISCUSSION QUESTIONS

1. What is the role of evidence-based research in policy development?
2. What are the facilitators and barriers of stakeholder engagement activities?
3. How does stakeholder engagement facilitate the implementation of an action plan?
4. What are the various characteristics of the stakeholders interested in Lyme disease engagement strategy?
5. Can international guidelines regarding emerging vector-borne infections be used to inform best practice guidelines in Canada?
6. How does the federal government perspective on Lyme disease differ from that of nonfederal and other external organizational perspectives? How does it impact stakeholder engagement?

### KEYWORDS

Communication; federal framework; Lyme disease; policy development; stakeholder analysis