REPORT OF THE LYME DISEASE AND TICK-BORNE ILLNESSES TASK FORCE

April 2018
Lyme Disease and Tick-borne Illnesses Task Force Membership

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This report was co-authored by the 12 full members of the Lyme Disease and Tick-borne Illnesses Task Force. While affiliations are listed, all members on the Task Force participated in deliberations as individuals and not representatives of their businesses, institutions or organizations/agencies. As such, the contents of this report, including all advice and recommendations, represent the views and opinions of the authors only. No endorsement by the Ministry of Health and Long-Term Care nor the affiliations for which the authors’ names appear is intended or should be inferred.
Letter from the Chair

Hon. Dr. Helena Jaczek
Minister of Health and Long-Term Care
Ontario Ministry of Health and Long-Term Care
10th Floor, Hepburn Block
80 Grosvenor Street
Toronto, Ontario M7A 2C4

Dear Minister Jaczek:

On behalf of the Lyme Disease and Tick-borne Illnesses Task Force, I am pleased to submit our final report to you. I would like to thank you for giving us the opportunity to offer advice and recommendations on a patient-centred approach to improving supports for Lyme disease and other tick-borne illnesses.

This report contains several key recommendations that we feel will improve the health and well-being of Ontarians affected by these diseases.

While the mandate of this group was not to review or develop new clinical care guidelines for Lyme disease and other tick-borne illnesses, this report does complement the work taking place at Public Health Ontario and Health Quality Ontario specific to the clinical management of tick bites as well as the mandate of the Lyme Disease Stakeholder Reference Group to inform the Ministry’s Lyme disease policy and programming.

We are hopeful that this information will be useful in the Ministry’s ongoing commitment to Lyme disease and other tick-borne illnesses and recommend that the report be released publicly to increase trust and hope among the Lyme disease community.

We would like to thank the Task Force’s Observers and Resource Members who provided valuable information throughout our series of meetings. We would also like to thank all members who provided input and feedback on the issues covered in this report.

We are confident that the information contained in this report will provide an opportunity for Ontario to reinforce its leadership position by adopting a patient-centred approach to Lyme disease and other tick-borne illnesses.

Sincerely,

Adalsteinn (Steini) Brown, Chair
Lyme Disease and Tick-borne Illnesses Task Force
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Executive Summary

Lyme disease and other tick-borne illnesses are having an increasing effect on the lives of Ontarians. We must continue to work with governments, public health units, regulated health professionals, patient advocacy groups, researchers, and other stakeholders to use evidence-based approaches to prevent and control these diseases, increase awareness of Lyme disease and other tick-borne illnesses among regulated health professionals and the general public, and address gaps in prevention, diagnoses, care, treatment and support through research.

Engaging with stakeholders to promote opportunities to further the dialogue regarding diagnosis, care, treatment, and support for people living with Lyme disease and other tick-borne illnesses is of great importance. As the science and the clinical management of these complex illnesses continue to evolve, we must not be complacent, but rather focus on actions to address this important matter.

In December 2017, 12 individuals were appointed to the Lyme Disease and Tick-borne Illnesses Task Force (the Task Force) by the Minister of Health and Long-Term Care to participate in a series of meetings in-person and via teleconference/webinar. Membership included Lyme disease patients, patient advocates and caregivers, regulated health professionals and academic researchers. Resource members provided additional information and expertise regarding Lyme disease and other tick-borne illnesses throughout the Task Force’s deliberations.

While the mandate of this group was not to review or develop new clinical care guidelines for Lyme disease and other tick-borne illnesses, this report does offer a number of recommendations including ten key priorities for immediate action:

1. Establish centres of excellence for tick-borne illnesses with all stakeholders, including patients and patient advocates and caregivers, involved in the development processes.
2. Conduct a review of current clinical practice guidelines focused on the assessment, treatment, and prevention of Lyme disease and other tick-borne illnesses.
3. Improve communications to regulated health professionals regarding standards of practice for diagnosing and treating Lyme disease and other tick-borne illnesses.
4. Provide professional education opportunities for regulated health professionals and establish a coordinated care model for patients with Lyme disease and other tick-borne illnesses at all stages of these diseases.
5. Improve education and awareness of tick-borne illnesses among the general public.
6. Continue engagement with school boards, community groups, associations, and other provincial ministries to highlight importance of tick-borne illness prevention.
7. Establish a community-based research blueprint for tick-borne illnesses with principles of inquiry and an implementation process.
8. Review current testing methodologies for diagnosing Lyme disease and other tick-borne illnesses.
9. Conduct a review of current tick surveillance activities in Ontario.
10. Establish a task force with tick-borne illness expertise and engagement with all stakeholders to provide ongoing advice and to review an annual report on progress of implementing Ontario’s 10-Step Education and Awareness Plan and the recommended actions from this report.
Longer-term recommendations are also included. These are designed to:

- increase knowledge and awareness of the seriousness of Lyme disease and other tick-borne illnesses;
- increase knowledge and awareness of the incidence of Lyme disease and other tick-borne illnesses throughout Ontario and the risks associated with contracting these diseases;
- standardize testing and diagnosis;
- engage patients in making fully informed treatment decisions;
- support ongoing collaboration between public health agencies, health regulatory bodies, outdoor and community organizations, patients, patient advocates and caregivers, and academia to keep stakeholders updated about tick-borne illness initiatives while more broadly disseminating education and awareness materials to Ontarians; and
- engage in research to identify the most effective interventions for controlling ticks, preventing tick bites, and improving testing and treatment Lyme disease and other tick-borne illnesses.

The Ministry of Health and Long-Term Care (the ministry) has shown great leadership and commitment to this issue and should continue to:

- provide support to those affected by Lyme disease and other tick-borne illnesses
- monitor the health landscape with regard to Lyme disease and other tick-borne illnesses; and
- respond to new information and research findings as they emerge.

The threat posed by Lyme disease and other tick-borne illnesses is increasing. We must work together to address the recommendations identified in this review so fewer and fewer Ontarians suffer from the devastating impacts of these diseases.

**Guiding principles**

The Task Force provided an opportunity to engage people with lived experience and those who care for people with Lyme disease and other tick-borne illnesses.

This report is guided by several key issues that inform the Task Force’s recommendations:

- We need to have a clear understanding of what we mean by Lyme disease.
- When people present with suspected or confirmed Lyme disease they need to be engaged in their care.
- Many Lyme patients experience stigma and frustration with our health system and are thus not able to access the supports and services they need.
- Current treatment and care standards for Lyme disease and other tick-borne illnesses must be reviewed in an inclusive, rigorous, and transparent manner by independent experts without conflicts of interest and driven by the best possible evidence.
- Regulated health professionals must receive training and education on how to properly diagnosis, treat and care for Lyme disease patients.
- Lyme disease is one of many tick-borne illness which can cause human disease. The United States Centers for Disease Control and Prevention (CDC) maintains a list of tick-borne illnesses that can be found globally.¹

¹ [https://www.cdc.gov/ticks/diseases/abroad.html](https://www.cdc.gov/ticks/diseases/abroad.html)
With these in mind, the Task Force offers a specific set of recommendations including some that are within capacity of the province and can be enacted immediately to make sure we are meeting current standards. All recommendations should be reviewed annually by a new task force.

We also recommend a set of further actions for which a new task force should be struck to work on.

**Background and introduction**

**What is Lyme disease?**

Lyme disease is the most common tick-borne illness in North America and is caused by the bacterium *Borrelia burgdorferi* (*B. burgdorferi*) (Public Health Ontario, 2016). In Ontario, Lyme disease is transmitted to people through the painless bite of an infected blacklegged tick (*Ixodes scapularis*) (Public Health Ontario, 2016). Other *Borrelia* species such as *B. garinii* and *B. afzelii* can also cause Lyme disease in humans. Some other species of ticks may also transmit other bacteria, protozoa, and viruses which can cause additional health complications (Biggs, 2016). Blacklegged ticks are very small (adults are the size of a sesame seed; nymphs that of a poppy seed) making them hard to see. A blacklegged tick often bites in a hidden part of the body and is painless. As a result, people may not realize they have, or have had, a tick feeding from them.

Nymphs are thought to account for the majority of human infections. The majority of cases occur in the spring and summer months as this is when the nympha stage of the blacklegged tick is most active, however infections can occur at other times as well.

Our understanding of Lyme disease is evolving. We are still learning about the different ways that Lyme disease may present and may be transmitted. As a result, we need more inclusive knowledge when discussing this disease.
Signs and symptoms

Early signs and symptoms of Lyme disease usually start three to 30 days following the bite of an infected blacklegged tick (Government of Canada, 2018). A classical Lyme disease presentation involves an erythema migrans (EM) rash (Health Quality Ontario, 2018), sometimes resembling a “bull’s-eye,” however not everyone infected by a tick with the Lyme disease bacteria will present with a rash. Other common symptoms include: fatigue, myalgia, headache, fever/chills, and stiff neck (Health Quality Ontario, 2018). Beyond these, additional symptoms can be experienced at different stages of the disease (Feder, 2007).

Throughout the Task Force’s deliberations, we heard from patients who have presented with a range of symptoms that overlap with other profound and debilitating diseases not recognized clinically.

The non-specificity of symptoms can also make diagnosis challenging – this underscores the need for improvements to education and awareness among health care providers and the general public about Lyme disease in all of its stages.

Epidemiology of Lyme disease in Ontario

Since 1988, when Lyme disease became a reportable disease in Ontario, the number of confirmed human cases has increased (Public Health Ontario, 2016). The number of confirmed and probable Lyme disease cases in Ontario more than tripled in 2017 (n=987)\(^2\), compared to the five-year (2012–2016) average (n=314) (Figure 2). Annual incidence rates have also increased since 2005, with the 2017 provincial rate more than twice that of 2016 (Figure 3).

\(^2\) Data pulled from the integrated Public Health Information System (iPHIS) on April 4, 2018. iPHIS is a dynamic disease reporting system which allows ongoing updates to data previously entered. As a result, data extracted from iPHIS represents a snap shot at the time of extraction and may differ from previous or subsequent reports.
Figure 2. Number of probable and confirmed Lyme disease case, by episode month, compared to five-year historical average (2012-2016): Ontario, 2017

Figure 3: Number of probable and confirmed Lyme disease cases and incidence rate per 100,000 population: Ontario, 2008 - 2017
Current tick surveillance activities in Ontario

Physicians and nurse practitioners are required to report individuals who have or may have Lyme disease to the local medical officer of health, who in turn reports all probable and confirmed cases to the ministry. Tick surveillance falls into two main categories:

Active surveillance – collecting ticks from their natural habitat through ‘tick dragging’ conducted by public health units.

Passive surveillance – examining ticks submitted to a health unit by the public.

Surveillance activities are inconsistent across the province and thus the prevalence of ticks in Ontario is likely underestimated.

The challenge

Lyme disease and other tick-borne illnesses are serious diseases affecting Ontarians of all ages, in all corners of the province. Although some people are diagnosed and treated effectively in the early stages of the diseases, this is not always the case. As a result, some individuals experience persistent symptoms and long-term complications that affect their physical, emotional, psychological, mental and financial well-being.

While proper diagnosis of Lyme disease should be clinical, based on signs and symptoms and supported by a history of possible tick exposure, many clinicians rely on a positive laboratory test before providing necessary treatments resulting in poor patient health outcomes (Ferrouillet, 2015; Henry, 2012). It is important for clinicians and public health officials to understand that these tests are designed to be used for surveillance purposes only.

Health care professionals should also be aware of the limitations of test results and the potential for false-positive and false-negative results. Serologic testing should merely supplement clinical diagnosis of Lyme disease and should not be the primary basis for making diagnostic or treatment decisions (Government of Canada, 2012). This is particularly important in the early stages of the disease as the optimal treatment window for best patient outcomes is immediately following an infected tick bite.

More work to be done – A call to action

While Ontario has made progress by acknowledging the need for action on Lyme disease and other tick-borne illnesses, there is still a lot to be done. We must:

- increase knowledge, education and awareness of Lyme disease and other tick-borne illnesses among regulated health professionals, public health authorities, and the general public;
- conduct research to improve testing methodologies;
- conduct research to better understand all stages of these diseases;
- standardize the criteria used to diagnose and treat Lyme disease and other tick-borne illnesses based on the best available evidence;
- offer additional supports to those suffering from tick-borne diseases; and
- take advantage of new and emerging technologies to collect and analyze province-wide tick data and recognize the emergence of new tick-borne illnesses in the province.
Opportunities for improvement

Our recommendations align with Patients First: Action Plan for Health Care. This plan commits to putting patients at the centre of the care they receive by:

- Providing faster access to the right care
- Delivering better coordinated and integrated care
- Supporting people and patients by providing education and information so they can make the right decisions; and
- Making evidence-based decisions on value and quality.

This report provides a guide for decision-making, program planning and partnership development going forward. The advice and recommendations provided will better position Ontario to leverage existing strategies, systems, agencies, communities, and individuals who are already making strides to educate, protect, and care for people affected by Lyme disease and other tick-borne illnesses. This report also offers opportunities for future discussion and collaboration.

Our mandate

The Task Force’s mandate was to provide advice and recommendations to the Minister of Health and Long-Term Care on a patient-centred approach to improving supports for acute Lyme disease and other tick-borne illnesses as well as the long-term complications associated with these diseases.

This mandate included providing input into the development of the ministry’s strategic framework for Lyme disease and tick-borne illnesses. The mandate did not include reviewing or developing new clinical care guidelines for Lyme disease and other tick-borne illnesses.

The Task Force was however asked to develop a set of recommendations that would build knowledge and capacity among regulated health professionals, and improve health outcomes and patient experience for those affected by Lyme disease and other tick-borne illnesses.

Specifically, the Task Force focused on identifying gaps in the delivery of care and ways to improve knowledge transfer and access to treatment and care for those at-risk of and affected by Lyme disease and other tick-borne illnesses.

Lyme Disease and Tick-borne Illnesses Strategic Framework for Action

This framework (see below) provides a road map for coordinated action that will address five pillars for action (outlined below) in collaboration with people with lived experience, advocates, academic researchers, governments, and community, professional and regulatory organizations.

The framework outlines the policy goal and objectives, as well as the key areas of focus and anticipated outcomes that will guide the development and implementation of a provincial Lyme disease and tick-borne illness strategy.
Figure 4: Lyme Disease & Tick-borne Illnesses: A Strategic Framework for Action in Ontario

<table>
<thead>
<tr>
<th><strong>GOAL</strong></th>
<th>To protect Ontarians from the health risks associated with Lyme disease and other tick-borne illnesses, and to progress towards more effective prevention and control measures, improved patient experiences, and bridging the dialogue between providers and those suffering from these diseases.</th>
</tr>
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</table>
| **OBJECTIVES** | 1. Reduce the number of Lyme disease and other tick-borne illnesses in Ontario  
2. More effectively determine risk in Ontario and shape public communications to improve awareness  
3. Work with stakeholders to create collaborative solutions on access to care  
4. Improve the case management, diagnosis, and availability of treatment and testing for Lyme and other tick-borne illnesses  
5. Learn how to better prevent and treat Lyme disease and other tick-borne illnesses through evidence-based research |
| **PILLARS OF ACTION** | **PREVENTION AND CONTROL**  
**SURVEILLANCE**  
**PUBLIC ENGAGEMENT**  
**CARE, TREATMENT, AND SUPPORT**  
**RESEARCH**  
| | | | | |
| **PROCESS** | Improve acute care of tick-borne illnesses through more effective case management  
Improve access to data sources, risk mapping, and other surveillance methods  
Improve collaboration between health care providers and those living with Lyme  
Establish collaboration to develop patient-focused diagnostic and treatment options  
Research new early identification methods to improve access to care |
| **RESULTS** | Reduced number of tick-borne infections in Ontario  
Increased awareness of the risk prevalence to inform public awareness  
Development of a Patient’s First approach to tick-borne case management  
Improved access to compassionate treatment of their diseases  
Improved understanding of the diseases and how to prevent/control them |
| **KEY ACTIVITY HIGHLIGHTS** | • Continue to implement the 10-step Education and Awareness Plan.  
• Host regular teleconference s with public health units to share information and best practices.  
• Revitalize public communication campaign to promote tick awareness.  
• Develop a comprehensive surveillance and monitoring policy for tick borne illnesses and other tick-borne illnesses.  
• Continue active and passive tick surveillance from spring through fall to inform annual estimated risk areas map.  
• Develop a Camp Directors’ working group to assist with direction on camp/child-focused communications tools.  
• Work with Ministry of Education to provide a joint-minister’s letter to school boards regarding awareness of Lyme disease and tick awareness.  
• Develop a diagnostic tool to assist HCPs to support diagnosis and tick bite management for acute tick borne illness (lead: HQO-PHO).  
• Develop a Lyme Task Force to provide input on activities under this framework.  
• Develop a tick-borne illness research agenda for Ontario. |
• **Prevention and control** – Reduce the rate of new infections through public education and advice on preventative measures.

• **Surveillance** – Improve data collection efforts and continue to monitor the spread of ticks and track incidence rates of human and animal cases.

• **Public engagement** – Establish/strengthen partnerships between patients, patient advocates and caregivers, regulated health professionals, and academic researchers to increase awareness of Lyme disease and other tick-borne illnesses amongst the general public.

• **Care, treatment and support** – Strengthen and target tick-borne illness education for regulated health professionals to enhance early detection and diagnosis with emphasis on Lyme disease infection via clinical and epidemiological findings, based on signs, symptoms, and possible tick exposure.

• **Research** – Improve laboratory diagnostic testing (sensitivity and specificity); collect and analyze data to update treatment guidelines; quantify/qualify impact of Lyme disease and other tick-borne illnesses on Ontarians in both the short and long-term.

**Recommendations**

The below recommendations have been organized according to the five pillars of the ministry’s *Lyme Disease and Tick-borne Illnesses Strategic Framework for Action*. The order in which the recommendations are listed does not reflect a hierarchy of importance.
The asterisk (*) in front of a recommendation denotes that this is a key priority for immediate action.

**Prevention and control**

*Improve education and awareness of tick-borne illnesses among the general public.*

It is important that we focus on improving Lyme disease awareness and ensure that public health messaging is age-specific and tailored to local contexts using plain language. Targeting public schools, camps, medical schools, health regulatory bodies, and individuals and organizations who work or spend time outdoors would be a good start.

It is important that we use the best available evidence in a consistent manner across the province so that people looking for information can find consistent messages from the Ontario government, its agencies and contracted providers.

Everyone in Ontario must know about the growing risk of Lyme disease and other tick-borne diseases and the seriousness and challenges associated with managing them.

Public messaging should acknowledge that adventitious ticks can be found anywhere and highlight:

- how Lyme disease occurs
- ideal tick habitats
- how to reduce the chances of being bitten by a tick
- how to properly remove a tick that is attached
- the signs and symptoms of Lyme disease stressing that:
  - there are a variety of Lyme rashes and sometimes there is no rash
  - a Lyme rash requires prompt medical treatment
- the seriousness of Lyme disease and the need for immediate medical attention if infection is suspected
- that Lyme disease is not the only tick-borne infection that can be transmitted by ticks
- the accuracy and limitations of testing

This messaging should be provided electronically, through traditional and social media channels and via brochures, flyers, fact sheets, and posters.

As people are often unaware that they have been bitten by a tick, it is important that this does not preclude regulated health professionals from thinking about the possibility of Lyme disease and treating people for Lyme disease to optimize health outcomes.

The ministry has stated that physicians who suspect a Lyme disease diagnosis in their patients should provide treatment immediately and not wait for test results.

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Enhance access to permethrin-soaked clothing and explore the effectiveness of other non-toxic tick repellants.

The Canadian military has facilitated the use of permethrin-soaked clothing and at least one company has filed to license to market permethrin-soaked clothing for the general public in Canada this spring. This information could be noted in ministry materials.

Safe and effective tick repellants are badly needed. Ontarians should have access to the methods of protection that are currently available in other endemic areas. Research should be initiated to better protect Ontarians from tick bites.

Create consistent prevention messaging.

Readily available information online is often conflicting, incomplete or inaccurate. It is important that the ministry provides reliable and consistent prevention messaging (in-line with federal, provincial and territorial partners) to all public health units in Ontario that is grounded in evidence-based behaviour change techniques.

Improve awareness of the signs and symptoms of Lyme disease and other tick-borne illnesses.

The general public must be made aware that prompt and proper removal of a tick reduces the risk of disease transmission. It is important to know that not everyone is aware they have been bitten by a tick. People need to be able to recognize the signs and symptoms of Lyme disease beyond a bull's-eye rash. Recognition of Lyme disease symptoms and knowing the importance of early diagnosis and treatment is the key to optimal health outcomes.

Continue the ministry’s public-facing campaign on ticks.

The ministry’s ongoing communications campaign, *Let’s Target Lyme*, has demonstrated effectiveness in improving the public’s awareness of how to recognize ticks, manage tick bites, the symptoms of Lyme disease, and ways to protect against tick bites. These should be continued and expanded where possible.

It is important that people know where they can get evidence-based consistent information. Any public-facing product/communication should include these details so that people are directed to reliable and consistent information.

**Surveillance**

*Conduct a review of current tick surveillance activities in Ontario.*

Currently, provincial surveillance relies on blacklegged ticks submitted by health units to Public Health Ontario. How a health unit captures these ticks varies, making it difficult to have accurate estimates of the number of ticks in a region, and how many of these might be infected with *B. burgdorferi* (positivity rate).

A review of current tick surveillance activities in Ontario should consider:

- The species of ticks that should be collected
- Adding specific tick-borne illnesses to Ontario’s list of diseases of public health significance
- Ticks on both private and public lands
- Different types of surveillance (i.e. active vs. passive)
- Ticks from animal companions

Conduct a review of current tick surveillance activities in Ontario.
• Utility of different approaches to screening including vectoral competency
• Range of animal reservoirs.

The results of this type of review could inform a formal tick surveillance plan for Ontario, improve the accuracy of Public Health Ontario’s risk-map, and allow for more transparent and accurate information that could be used by regulated health professionals and the general public with respect to prevention and diagnoses of Lyme disease and other tick-borne illnesses.

**Use and integrate a variety of data sources.**

The integration of existing data platforms would help create a more robust surveillance system. This includes exploring the feasibility and effectiveness of a data infrastructure plan that encompasses: animal data (ticks submitted through veterinarians); citizen science; modern technologies such as eTick); tick collection on private lands; and partnerships with individuals who collect wildlife species that are known reservoir species (i.e. wild mice, squirrels, coyotes, etc.). By diversifying our data collection methods, we could have better estimates of ticks in the province while providing evidence to support more targeted prevention efforts.

**Update Public Health Ontario’s Lyme disease risk map.**

It is important that people are aware that adventitious ticks can be found anywhere in the province and that Ontario’s current risk map\(^4\) can be used to give individuals a false sense of security about their risk of Lyme disease when they are outdoors. Further, regulated health professionals can be confounded when patients present with Lyme symptoms without having visited or lived in an identified high risk area. Advocacy groups and patients report that this has been known to result in the absence of a Lyme diagnosis even with the presentation of symptoms.

Ticks populations change and expand over time due primarily to bird and animal migration and changes in climate. As a result, this map should be updated to not only focus on risk areas but to more clearly identify all parts of the province as potential tick areas.

The map should also provide cumulative numbers, historic trends, numerators, denominators, positivity rates, and an overlay of human cases to provide more context for the determination of risks.

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\(^4\) [https://www.publichealthontario.ca/en/BrowseByTopic/InfectiousDiseases/Pages/ILandingPages/Lyme-Disease.aspx](https://www.publichealthontario.ca/en/BrowseByTopic/InfectiousDiseases/Pages/ILandingPages/Lyme-Disease.aspx)
Public engagement

*Establish a task force with tick-borne illness expertise and engagement with all stakeholders to receive an annual report on progress of implementing Ontario’s 10-Step Education and Awareness Plan and the recommended actions from this report.

The ministry has shown great leadership and commitment with respect to Lyme disease and tick-borne illnesses through the establishment of this Task Force as well as the launch of Ontario’s 10-Step Education and Awareness Plan in July 2016. It is important to keep the momentum going. To increase trust and hope among the Lyme disease community, an annual report on progress made implementing the recommendations from the 10-step plan as well as this report should be posted on the ministry’s website.

In addition, a new task force with representation from advocacy groups, people with lived experience, academic researchers, public health units, and regulated health professionals with tick-borne illness expertise should be established to provide further advice, comment and recommendations to the ministry in order to achieve our collective goal of improving the lives of people affected by Lyme disease and other tick-borne illnesses. Deliberations should be completed in time for the upcoming season.

*Continue engagement with school boards, community groups, associations, and other provincial ministries to highlight importance of tick-borne illness prevention.

We must engage in outreach activities with a broad range of stakeholders. This work has been initiated with the formation of the Lyme Disease Stakeholder Reference Group whose work should continue. We should also leverage existing community and health system partnerships by conducting outreach activities targeting the following: Ontario Medical Association; organizations and associations for veterinarians, social workers, nurse practitioners, pharmacists, dentists, physiotherapists, chiropractors, and naturopaths; the Mental Health Commission of Canada, public health units; the Ontario College of Family Practitioners, the Association of Municipalities of Ontario, the association of Local Public Health Agencies; outdoor sport associations such as the Ontario Golf Association, organizations representing outdoor workers, as well as all provincial ministries, most notably the Ministries of Education, Labour, and Natural Resources and Forestry.

We should also incorporate tick bite prevention and tick-borne disease education in schools, as has been done in other jurisdictions. Providing age-appropriate information in schools, including as part of school curricula, and distributing letters to parents would improve tick awareness and the importance of taking tick bite precautions.
Include tick-borne illness materials in packages for hunting/fishing license renewals

Each year, hundreds of thousands of Ontarians renew their outdoor cards and purchase hunting and fishing licenses through the Ministry of Natural Resources and Forestry. The ministry should collaborate with the Ministry of Natural Resources and Forestry, the Ontario Federation of Anglers and Hunters, and other pertinent agencies to include information on Lyme disease and other tick-borne illnesses in annual license renewal packages.

Undertake knowledge translation activities through patient group websites and patient conferences and events.

Conducting research and establishing a knowledge base is only as successful as efforts to disseminate this information. All research conducted should include a well thought-through knowledge translation plan that engages Lyme disease patients and advocacy groups.

Care, treatment and support

*Establish centres of excellence for tick-borne illnesses.

Establishing centres of excellence would provide academic researchers and regulated health professionals throughout the province an opportunity to collaborate and share knowledge to improve patient outcomes.

In alignment with the Patients First: Action Plan for Health Care which commits to putting patients at the centre of the care they receive, these centres could: Provide coordinated care and treatment for people with Lyme disease and other tick-borne illnesses including those with complex presentations; ensure follow-up and monitoring of patients; support collaboration between university-based researchers with relevant expertise and academic health science centres that train regulated health professionals; and promote evidence-based policies and programs. These centres should be developed with the full participation of patients, patient advocates, and caregivers.

Tick-borne illness testing, diagnosis, care, and best treatment practices are evolving. Ontario can play a leading role in this with such an initiative.

*Improve communications to regulated health professionals regarding standards of practice for diagnosing and treating Lyme disease and other tick-borne illnesses.

We must do a better job of communicating with regulated health professionals that Lyme disease incidence rates are increasing in Ontario and that diagnosis and treatment of suspected cases of Lyme disease should be based primarily on their clinical and professional judgement in-line with publicized government standards. As serological testing may not yield accurate results during early localized Lyme disease, when treatment is most effective, it is important that clinicians manage potential and/or suspected cases of Lyme disease primarily on clinical judgement.

Advocacy groups and patients report that physicians may not consider a Lyme diagnosis for several reasons including: the uncertainty of a known tick bite, the misunderstanding that infected ticks are found only in known risk areas, the lack of an EM rash or laboratory
confirmation. In these instances, patients are put in a position of having to advocate for themselves when it comes to obtaining a diagnosis, interpreting test results and/or having to make a case for treatment.

As EM rashes are not always present after a tick bite, an assessment of other signs and symptoms of Lyme disease is important. These include: fever, heart block or arrhythmias, cranial nerve palsies, lymphocytic meningitis, conjunctivitis, arthralgia, myalgia, fatigue and subtle cognitive difficulties (Fuster, 2017). Factors regarding medical history and travel should also help with clinical decision-making.

Advocacy groups and patients report that undetected/misdiagnosed/insufficiently treated individuals end up being referred to numerous regulated health professionals while undergoing additional tests and inappropriate treatments. These individuals may end up presenting in emergency rooms in an attempt to manage their symptoms. Oftentimes patients are offered referrals to mental health services to ‘deal with their issues.’

Further, advocacy groups and patients report that after experiencing a poor response to their health needs in Ontario, individuals often seek medical diagnoses and treatment in the United States at a considerable personal cost. Unfortunately, the majority of people simply cannot afford this option, and many can become reluctant to access the Ontario medical system any further due to the feelings of humiliation and stigmatization they experience when they do.

Establishing evidence-based guidelines for the diagnosis and treatment of Lyme disease and other tick-borne illnesses that are well-understood and followed by all regulated health professionals and accessible to patients would dramatically improve patient experiences.

*Provide professional education opportunities for regulated health professionals and establish a coordinated care model for patients with Lyme disease and other tick-borne illnesses at all stages of these diseases.*

Advocacy groups and patients report that many physicians do not think that ticks are an issue across all of Ontario. Two Canadian studies have explored Lyme disease knowledge among physicians. A 2012 study of pediatricians, family practitioners, and internal medicine specialists from British Columbia found that less than 30% were aware that an EM rash alone was diagnostic for Lyme disease (Henry, 2012). A 2015 study from Quebec found a moderate lack of knowledge and sub-optimal practices among family practitioners (Ferrouillet, 2015).

Having an algorithm or ‘red-flag’ system in place for clinicians to investigate and manage effectively tick-borne illness cases would create consistency and ensure that people are given prompt treatment. Through a Public Health Ontario-Health Quality Ontario partnership, some of this work is already underway. It is important that we improve knowledge of signs and symptoms among regulated health professionals to avoid misdiagnoses.

People with Lyme disease and other tick-borne illnesses often require additional supports and access to social services. It is not good enough to only provide narrowly defined medical care to patients who present with one of the many stages of Lyme disease or other tick-borne illnesses. Oftentimes, Lyme disease and other tick-borne
illnesses affect people emotionally, psychologically and financially and this requires as much attention as medical treatment.

It is also important that patients are involved in discussions about their treatment course. Patients should be aware of the benefits and potential side effects of all treatment options so that they are in a position to make informed decisions about their care.

While a patient might see several different regulated health professionals during their illness, it is important to have one person at the centre of this care who is aware of all aspects of the patient’s situation and can follow-up at regular intervals if symptoms do not subside.

Destigmatizing Lyme disease and other tick-borne illnesses, particularly among regulated health professionals, is also crucial to a coordinated care model for Lyme disease treatment and care. It is important that regulated health professionals are comfortable working with patients who present with a tick-borne illness or have concerns that they may have contracted one.

Offering continuing medical education events specific to Lyme disease and other tick-borne illnesses could improve knowledge among regulated health professionals while offering a platform to have explicit discussions of tick-borne illnesses so that individuals are up-to-date on the most recent evidence specific to diagnosis and treatment and can provide the best care for their patients. Individuals with lived experience should be involved in planning and presenting at these events.

Create tick-borne illness specific training for medical residents.

A large number of Ontario-based physicians have never diagnosed or treated a patient for Lyme disease or any other tick-borne illness. Offering tick-borne illness-specific training to medical residents in Ontario could go a long way in closing this practice gap. Individuals with lived experience should be involved in establishing this training.

Research

*Work with patients, providers, and researchers to establish a community-based research blueprint with strong emphasis on knowledge transfer.*

We must conduct research to establish and promote a clear definition of what Lyme disease is. This can be done using the James Lind Alliance approach which is designed to change the way research funding is granted and raise awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them. The first step in prioritizing this agenda would be to convene a symposium with a group of Lyme patients, patient advocates and caregivers, academic researchers, and regulated health professionals to develop a research strategy for Ontario.

All research should take place in accordance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans,\(^5\) and the principles of community-based research, which states that community representatives (Lyme patients, advocates and caregivers) must be involved in all aspects of the research process – setting the research agenda, designing and conducting trials and studies and presenting and disseminating findings (Israel, 2012).

Research should be prioritized across the following themes:

- Preventatives
- Co-infections
- Diagnostics
- Disease mechanisms
- Human biology
- Therapeutics

See appendix A for an expansion on these themes.

*Conduct a review of current clinical practice guidelines focused on the assessment, treatment, and prevention of Lyme disease and other tick-borne illnesses.*

In North America there are currently two major clinical practice guidelines in use:

- The Clinical Management of Known Tick Bites, Erythema Migrans Rashes and Persistent Disease (International Lyme and Associated Disease Society, 2014)

Unfortunately, these guidelines offer conflicting recommendations for how to diagnose and treat Lyme disease in all its stages.

Considering these, Ontario should conduct a review of its current standards of treatment and care of Lyme disease and other tick-borne illnesses in an inclusive and transparent manner by independent experts, without conflicts of interest, using rigorous, accepted and reproducible methods such as those used by the Cochrane Collaboration and Joanna Briggs Institute. Any updates to current practices must be driven by the best available evidence and applicable to the Ontario and Canadian context.

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6 The United Kingdom’s National Institute for Health and Care Excellence is currently in consultation phase on a guidance document to help general practitioners, specialists and other health professionals spot a potential diagnosis of Lyme disease.
7 http://www.idsociety.org/Guidelines/Patient_Care/IDSA_Practice_Guidelines/Infections_By_Organism-28143/Bacteria/Lyme_Disease/
8 https://www.ncbi.nlm.nih.gov/pubmed/25077519
9 http://www.cochrane.org/
10 http://joannabriggs.org/
*Review current testing methodologies for diagnosing Lyme disease and other tick-borne illnesses.*

Lyme disease test kits have sensitivity and specificity limitations (Government of Canada, 2012). Currently used Lyme disease test kits are not designed to screen patients or to establish a clinical diagnosis (Government of Canada, 2012). These tests are primarily designed for surveillance purposes.

As a result, a review of global testing technologies should take place and tests offering the best combination of sensitivity and specificity, as determined through an independent review of the best available evidence, should be used in Ontario.

Health care professionals should also be aware of the limitations of test results and the potential for false-positive and false-negative results. Serologic testing should merely supplement clinical diagnosis of Lyme disease and should not be the primary basis for making diagnostic or treatment decisions (Government of Canada, 2012). This is particularly important for patients with acute infection as Lyme disease at this stage, when suspected, can be effectively treated with antibiotics. It is important to note however, that even when test results are conclusive, the time it takes to submit a blood sample and receive the test results back is often lengthy. Exploring new testing technologies and improving current lags in submitting test samples and receiving results must be improved so as not to impede the effect that immediate antibiotic treatments could have in halting the progression of the disease.

**Conduct a systematic review focusing on treatment of Lyme disease and the long term complications associated with the illness.**

A systematic review summarizes evidence from research to help inform recommendations for healthcare.

These reviews follow a consistent, pre-determined, and methodologically rigorous and reproducible format that depends largely on what research evidence is available, the quality of the studies conducted and the health outcomes that were measured. The Cochrane Collaboration and Joanna Briggs Institute are two highly reputable organizations that offer methods to conduct these reviews.

There has yet to be a systematic review focused on the long-term complications associated with Lyme disease.

As these reviews represent an international gold standard for high quality, trusted information, a systematic review on this topic could help shape our treatment and care practices.
Conduct research into areas of promise based on prioritization as determined by patients, providers, and researchers involved in establishing the community-based research blueprint.

Examples of research that could take place include:

- **Exploring the relationship between Lyme disease and mental health issues.**
  
  Studies have shown associations between Lyme disease and depression, anxiety, and other psychiatric symptoms. Research should be conducted to better understand these links and how they can be prevented and treated to reduce complex co-morbidities often associated with Lyme disease.

  **Determining the mechanisms that occur at a molecular level among humans and animals infected with B. burgdorferi.**

  Understanding the molecular mechanism in humans and animals infected with B. burgdorferi could shed light on effective treatment courses.

- **Exploring the long term complications of Lyme disease.**

  The mechanisms and magnitude of tissue damage among Lyme disease patients suffering from persistent symptoms is not well understood. Research in this area could highlight the need for early treatment and the effects of long-term antibiotic treatments.

- **Exploring the effectiveness of integrative medicine interventions for Lyme disease patients.**

  Many individuals seek care outside the traditional biomedical model. The integrative approach to care focuses on the whole person and the relationship between regulated health professionals and patients. It offers a personalized approach to care that considers each person’s needs and circumstances and provides options to treat illness, and regain or maintain optimal health.

  Increasingly, integrative practitioners are overseeing the management of persistent symptoms attributed to Lyme disease among individuals in their practice. Understanding the effectiveness of these interventions could improve health outcomes for Lyme patients.
Gaps that still need to be addressed

Implementing the recommendations in this report would go a long way to improving prevention efforts and the care, treatment and support that Lyme patients currently receive.

While several items were out-of-scope for this Task Force, advocacy groups and patients would like to see additional ministry-support to explore the following:

- Current rates of adherence to standards among regulated health professionals and public health agencies specific to prevention, treatment, diagnoses and non-stigmatizing care.
- Reducing the number of individuals who seek care outside of Ontario and Canada and face challenges bringing medications back into this country and getting appropriate care maintained within the Ontario Health Insurance Plan system.
- Adding several tick-borne illnesses to the list of diseases of public health significance for broader surveillance, prevention, reporting and monitoring.
- The need to explore how Lyme disease patients experience other illnesses, including co-infections and how this impacts the care they receive in our health system.
- The need to explore the risk of Lyme disease infection through vertical transmission, breastfeeding, blood donations, organ/tissue transplantations etc.
- Collaborating with insurers, the Ministry of Labour, and other organizations so that Lyme disease patients can access goods and services available to the general public.

How should we measure success?

While the implementation of the recommendations in this report is an important step toward preventing Lyme disease and other tick-borne illnesses in Ontario, measurable targets must be established to monitor how effectively we are achieving our goals.

The focus should be on:

- Controlling and reducing the rates of new infections.
- Expanding and ensuring consistency of surveillance efforts.
- Increasing knowledge and awareness of tick-borne illnesses among regulated health professionals and members of the public.
- Improving access to streamlined, integrated care, treatment and support for those with suspected or confirmed Lyme disease.
- Measuring, using validated instruments, and improving patient experiences and other outcomes important to Lyme patients and caregivers.
- Improving our understanding of these diseases and their long-term complications.

The targets will enable us to know how much closer we are to achieving our goals.
**Moving forward together**

Putting recommendations into practice can take time, however many of the items highlighted in this report have already begun or simply need to continue with explicit direction from government and regulatory bodies.

While some of the longer-term recommendations may take a year or more to implement, the key recommendations for immediate action could be implemented in the next six to 12 months.

An evaluation of the impact of all recommendations put forward in this report should be conducted and updates on progress should also be provided to the public on an annual basis so that any necessary improvements can be made in a transparent manner and in consultation with relevant parties.

Implementing these recommendations will require collaboration between regulated health professionals, academic researchers, community advocates, patients and caregivers.

**Shared commitment**

There are many individuals, organizations and regulated health professionals involved in providing care to people suffering from Lyme disease and other tick-borne illnesses in Ontario. To be more responsive and solution-oriented, our health care system will need to rely on collaboration between all these groups. Thus, it is hoped that the actions recommended in this report will have the support of all parties so that by working hand-in-hand we can enact the proposed strategic framework and improve prevention and control, surveillance, public engagement, care, treatment and support, and research activities throughout the province.

The recommendations provided in this report demonstrate the power of working together to achieve a common goal in strengthening and improving Ontario’s’ response to Lyme disease and other tick-borne illnesses.
References


Appendix A – Proposed research blueprint from the community perspective

**Philosophy**

**Disease Model & Research Definition:** should be holistic, developed with stakeholder consultation to capture a spectrum of clinical Lyme cases for investigation. Complex and chronic disease manifestations should be emphasized; serological findings should not be used to exclude participants.

**Patient Involvement:** stakeholders must be engaged in determining research areas and informing study designs. They should have access to research outcomes through various channels including open-access publications, symposia, and lay abstracts distributed through advocacy networks.

**Priority Setting:** use literature reviews in parallel with patient recommendations to identify focus areas.

**Ethical Practices:** all studies must meet the most stringent ethical requirements of TCPS2, AoIR3, TCPS3 for specimen banking, use of medical records, big data surveys.

**Topics**

<table>
<thead>
<tr>
<th>Preventatives</th>
<th>Co-infections</th>
<th>Diagnostics</th>
<th>Disease mechanisms</th>
<th>Human biology</th>
<th>Therapeutics</th>
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<tbody>
<tr>
<td>Tick repellents (physical, chemical)</td>
<td>Unbiased environmental monitoring (broad pathogen screens in ticks, reservoirs)</td>
<td>Primary care dx algorithm</td>
<td>Vector competency (flies, mosquitoes)</td>
<td>Prodisposition (genetics, lifestyle, environment, trauma)</td>
<td>Optimal antimicrobial treatment protocols (prophylaxis, combination therapy, functional mod / integrative treatment, re-treatment, re-purposed pharmaceuticals / nutraceuticals)</td>
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<tr>
<td>Ecological strategies (eg: calling reservoir species)</td>
<td>Companion animal surveillance</td>
<td>Emerging dx technologies</td>
<td>Human transmission routes (congenital, sexual, contact, blood and organ donation)</td>
<td>Complications (immune regulation)</td>
<td>Novel anti-spirochetal compounds</td>
</tr>
<tr>
<td>Vaccines (1 or more IBX2)</td>
<td>Human diagnostics informed by environmental prevalence</td>
<td>Novel targets / testing paradigms</td>
<td>Bacterial persistence strategies (biofilm, antimicrobial tolerance)</td>
<td>Co-morbidities (EBV, mycotoxicity etc.)</td>
<td>Immunomodulatory intervention</td>
</tr>
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**Integration:** Connect clinical centres of excellence to multidisciplinary academic research nodes, harmonize processes and philosophies, involve commercialization partners as required.

**Knowledge Mobilization** Work with health agencies, regulatory bodies, clinicians, stakeholders and users throughout the investigations to ensure that research studies are ‘actionable’ (scale and scope are appropriate to influence policy, best practices). Ensure that findings are disseminated along relevant channels.

**Continuity of Care:** Determine how individual patients’ ‘research results’ will influence their care in the Ontario health system.