

# Towards Trust: Policy Initiatives for Vaccine Confidence through Transparency and Education



Cody Malone, Rafael Fernandes Ferreira, Audrey Corbeil, and Taylor Volappi

Lyme disease is an emerging public health threat in Canada as black-legged ticks are rapidly spreading across the country. Lyme disease has become a significant economic burden on the Canadian healthcare system. Currently, no vaccines are commercially available, but several are in development. Previous Lyme disease vaccines created fear and uncertainty about vaccine safety. We suggest an innovative and centralized database regularly updated with open, transparent vaccine safety information to empower the public and patients with easily accessible resources and knowledge. Our online public information platform will also include resources and training modules for healthcare professionals. Our goal is to provide transparent and timely information through non-governmental organizations to restore trust, while empowering the public to make risk-based and informed decisions regarding Lyme disease prevention.

## Beyond the Bite: The Multi-faceted Impact of Lyme Disease on Public Health in Canada

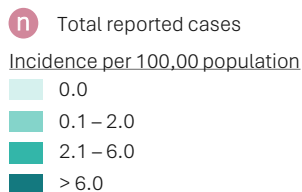
Lyme disease is an escalating public health issue in Canada, driven by an annual increase in cases, exceeding 3000 confirmed cases in 2021. This rising number of cases has been attributed partially to climate change, which is facilitating the northward expansion of ticks, coupled with increased surveillance and awareness, resulting in more cases being detected.<sup>1-4</sup>

Lyme disease is caused by the bacteria *Borrelia burgdorferi*, which can be transmitted to humans through the bite of infected black-legged ticks, also known as deer ticks or *Ixodes scapularis*. The clinical manifestations of Lyme disease are complicated and can often lead to misdiagnoses. Early detection and treatment are critical for successful outcomes. If left untreated, this disease can lead to serious health complications affecting the joints, heart, and nervous

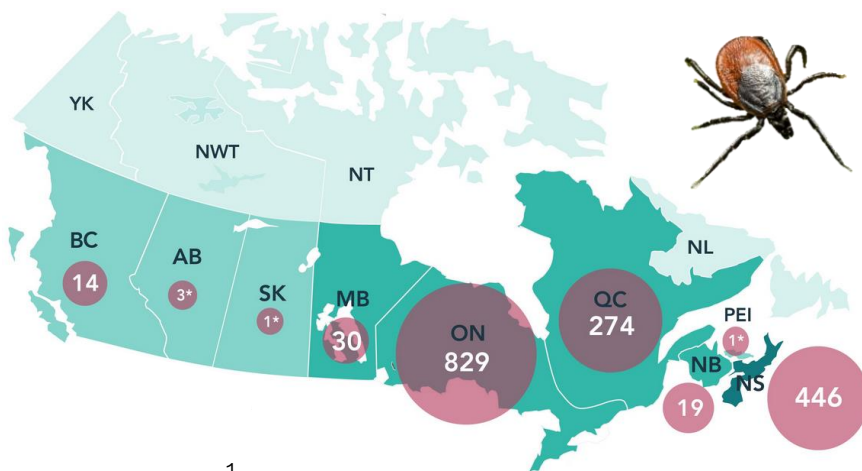
system. In addition, some patients can also endure prolonged, non-specific neurological issues that last for years, which can have significant quality of life and monetary cost, as the long-term sequelae of Lyme disease can be more expensive if left untreated at the onset, when treatment is crucial.

The economic costs and the burden of the healthcare system are substantial and continuing to increase in Canada. This trend is expected to escalate to an estimated incidence reaching 120,000 to 500,000 cases per year in Canada by 2050, at a projected cost of CA\$0.5 to \$2 billion annually.<sup>5</sup> This economic burden is associated with healthcare costs, and productivity loss due to impaired quality of life.<sup>6</sup> Currently, the cost per Lyme disease patient from pre-diagnosis to post-acute care is estimated to be approximately \$3000 in Ontario and is likely to be higher in non-endemic areas.<sup>4, 6</sup>

Geographic distribution of all reported Lyme disease cases by the black-legged tick in Canada, 2020.<sup>7</sup>



\*Cases reported by AB, SK, and PEI were travel-related only



## Hesitancy to Transparency

Current recommendations for the prevention of Lyme disease are limited to trying to prevent tick bites by wearing appropriate clothing, using insect repellent in high-risk areas, and conducting thorough tick checks after spending time outdoors. However, these efforts have shown limited effectiveness in reducing the infection.<sup>8</sup> For the past twenty years, there has been a gap in prevention since a Lyme disease vaccine was introduced to the market in 1998 but it was abruptly withdrawn from the market only three years later due to poor sales, negative publicity, and misinformation about safety concerns.<sup>8</sup> This scenario has inevitably led to skepticism and hesitancy regarding future Lyme disease vaccines, which has delayed the development of new Lyme disease vaccines. However, several vaccines are currently in development, and it is crucial that government agencies in Canada are prepared to scrutinize the vaccine and effectively **provide transparent information to the public** so that individuals can make informed decisions.

It is widely recognized that disease prevention is the most cost-effective method, and one of the greatest tools for prevention is vaccination.<sup>8-10</sup> Furthermore, vaccination might decrease the need for antibiotic therapy, the associated risks of antibiotic resistance, and adverse effects.<sup>10,11</sup> This approach could also substantially reduce the incidence of Lyme disease, thereby alleviating the burden on healthcare resources and enhancing public health outcomes.<sup>12</sup> Nonetheless, there are multiple challenges that could impede the acceptance of a novel vaccine for Lyme disease.

The World Health Organization has identified “reluctance or refusal to vaccinate despite the availability of vaccines” as one of the ten threats to global health in 2019.<sup>13</sup> Safety and fear of vaccine side effects were the primary concerns among Canadian parents during the COVID-19 pandemic,<sup>2</sup> mirroring issues surrounding the previous Lyme vaccine.<sup>11</sup> Misinformation should also be considered, as it can spread through various channels such as social media and anti-vaccine groups, perpetuating misconceptions

and impeding constructive discussions about Lyme disease prevention.<sup>11</sup> Therefore, several crucial factors must be considered to mitigate vaccine hesitancy and improve the acceptance of Lyme disease vaccination, with a focus on transparency from government agencies and pharmaceutical companies.

Currently, Canada has systems for reporting vaccine adverse events (e.g., Canadian Adverse Events Following Immunization Surveillance System (CAEFISS)), data on black-legged tick risk areas, and mandatory physician reporting of Lyme disease cases. However, these systems do not work harmoniously. This information is fragmented, difficult to find online, and often requires individuals to visit many websites published by different government agencies. This is an issue of concern as it acts as a barrier to transparency and ease of access.

Physician understanding of Lyme disease symptoms is another crucial area of concern, particularly in areas where black-legged ticks have recently expanded. The public’s trust in healthcare providers is important, as many individuals rely on physicians as their primary source of vaccine safety information, often looking for a recommendation.<sup>2,12</sup> Unfortunately, the Canadian system has had issues with physicians surrounding Lyme diagnosis, including many patients feeling frustrated or concerned following their physician’s diagnosis or misdiagnosis.<sup>4</sup>

As Lyme disease is not transmitted human-to-human, the decision to receive the vaccine should be based on individuals assessing their risk of exposure to infected ticks and carefully weighing the advantages and disadvantages of vaccination.<sup>9</sup> Our goal is to create an easy-to-access, informative, and transparent online platform that offers comprehensive information about approved Lyme vaccines and encourages individuals to make informed decisions about whether vaccination is suitable for them. The platform will inherently promote empowerment and self-agency, which are significant components of restoring trust. With the upcoming and likely release of a new Lyme disease vaccine, it is paramount that data be readily accessible and regularly updated for the public.



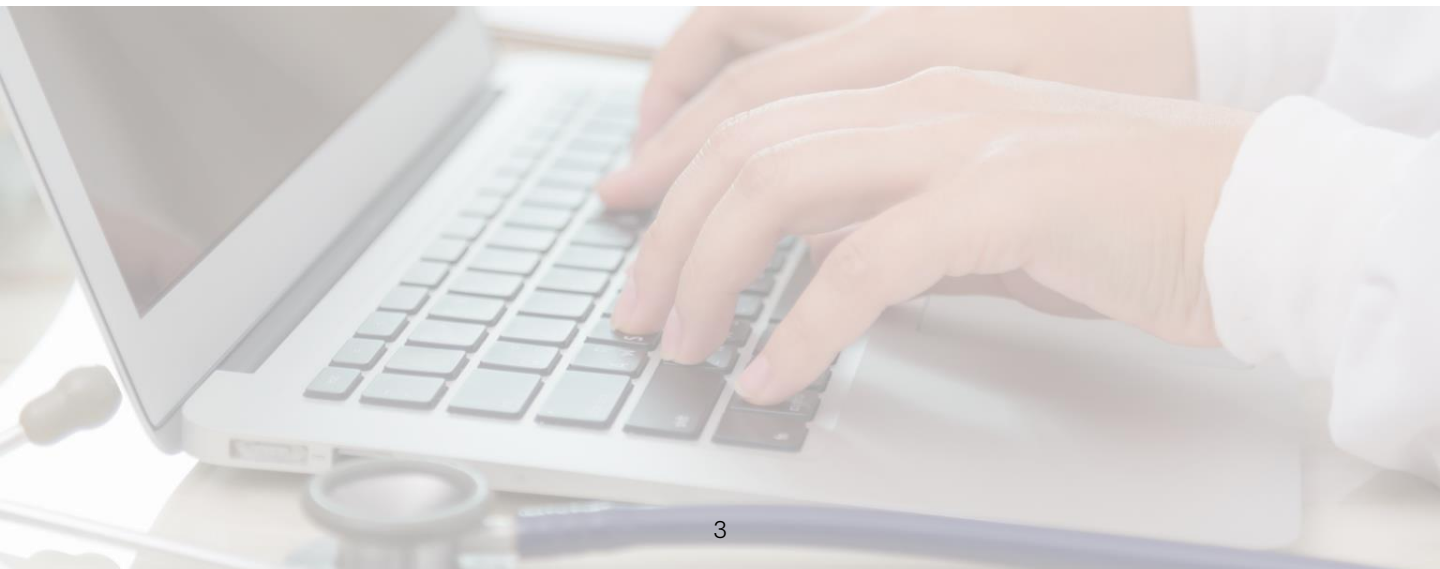
## Policy Initiative: Bridging Knowledge Gaps with A Comprehensive Platform for Information Sharing

**1** Our program plans to bridge the current gap of distrust between the public and the public health system by implementing a fully transparent online platform that will provide all the information necessary for the public to make their own informed decisions about whether the Lyme disease vaccine is right for them. Our proposal aims to merge the current Canadian framework for Lyme disease centered on disease surveillance,<sup>2</sup> education and awareness, guidelines, and best practices as well as the current initiative towards open science.<sup>14</sup>

- A.** The platform will allow the provincial/territorial governments to post materials, recommendations, and guidelines on the platform regarding prevention and who in their respective province/territory may be a candidate for vaccination.
- B.** Provide training courses for healthcare professionals to update their knowledge of Lyme disease to provide the best patient care (e.g., case definition, symptom recognition, diagnosis, treatment, vaccine information and adverse effect reporting, proper tick removal technique).
- C.** Support information for people living with Lyme disease, story sharing, patient advocacy group resources, medical resources.
- D.** Information platform for the public to access up-to-date information on Lyme disease cases, range of black-legged ticks, endemic areas, vaccine information and adverse effect reporting, and Lyme disease prevention techniques.
- E.** Platform Publicity: Place promotional flyers in health centers and pharmacies. Partner with outdoor recreation associations and parks to promote the platform (flyers, posters, or QR code at the entrance to a mountain or hiking trail).

**2** This policy also aims to enlist the support of non-governmental organizations (NGOs) to play a significant role in monitoring post-vaccination data, particularly those related to adverse effects, long-term efficacy, and safety of vaccines.

- A.** NGOs would serve as independent stakeholders to monitor, collect, and analyze data obtained from healthcare systems and research institutions to ensure the transparency and reliability of vaccine-related information. This may include parties such as CanLyme, the Nova Scotia Infectious Diseases Expert Group, patient advocacy groups, or the Association of Medical Microbiology and Infectious Disease Canada.
- B.** Continue ongoing surveillance of adverse effects by establishing follow-up mechanisms to monitor individuals who have received the vaccine. Their independent oversight is crucial in ensuring transparency, accuracy, and public confidence in vaccination initiatives.



## Simple and Solid Foundations to Rebuild a Legacy of Trust

This policy aims to restore the public's trust when it comes to messaging from government agencies. This policy is directed toward the Lyme disease vaccine, but it could be adapted to future vaccine developments. The program will provide an easy-to-access and regularly updated website where the public can access all the information they may require to make their own informed decisions based on the available data. Restoring trust is essential for the uptake of the Lyme disease vaccine therefore this platform aims to be an important tool in restoring that trust by providing the most transparent and unbiased "one-stop-shop" for Lyme disease vaccine adverse events, information on the geographic range of

black-legged ticks, Lyme disease case reports by region, and any federal and provincial or territorial messaging, including their local recommendations on vaccination. **Consequently, this policy also seeks to educate and empower these stakeholders to disseminate and promote the benefits of vaccination, while facilitating user access to all data available on the platform.** Building confidence and decreasing vaccine hesitancy in the context of Lyme disease vaccination includes improving the transparency regarding information shared about vaccination, having accessible knowledge/training for healthcare professionals and consumers, and maintaining a surveillance system for epidemiological monitoring and reporting.



### References

1. Stark, J. H. et al. Intention to vaccinate for Lyme disease using the Health Belief Model. *Zoonoses Public Health*, doi:10.1111/zph.13107 (2024).
2. Public Health Agency of Canada. "Lyme Disease in Canada - a Federal Framework." Canada.ca, May 29, 2017. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/lyme-disease-canada-federal-framework.html>.
3. Kullberg, B. J., Vrijmoeth, H. D., van de Schoor, F. & Hovius, J. W. Lyme borreliosis: diagnosis and management. *BMJ* 369, m1041, doi:10.1136/bmj.m1041 (2020).
4. Levesque, M. & Klohn, M. A Multiple Streams Approach to Understanding the Issues and Challenges of Lyme Disease Management in Canada's Maritime Provinces. *Int J Environ Res Public Health* 16, doi:10.3390/ijerph16091531 (2019).
5. Ogden NH, Dumas A, Gachon P, Rafferty E. Estimating the Incidence and Economic Cost of Lyme Disease Cases in Canada in the 21st Century with Projected Climate Change. *Environ Health Perspect.* 2024;132(2):27005.
6. Mac, S., Evans, G., Pullenayegum, E., Patel, S. N. & Sander, B. Healthcare costs and outcomes associated with laboratory-confirmed Lyme disease in Ontario, Canada: A population-based cohort study. *PLoS One* 18, e0286552, doi:10.1371/journal.pone.0286552 (2023).
7. Public Health Agency of Canada. "Lyme disease surveillance in Canada: Annual edition 2020." July 27, 2023. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/lyme-disease-surveillance-canada-annual-edition-2020.html>.
8. Shen, A. K., Mead, P. S. & Beard, C. B. The Lyme disease vaccine--a public health perspective. *Clin Infect Dis* 52 Suppl 3, s247-252, doi:10.1093/cid/ciq115 (2011).
9. Plotkin, S. A. Correcting a public health fiasco: The need for a new vaccine against Lyme disease. *Clin Infect Dis* 52 Suppl 3, s271-275, doi:10.1093/cid/ciq119 (2011).
10. Nigrovic, L. E. & Thompson, K. M. The Lyme vaccine: a cautionary tale. *Epidemiol Infect* 135, 1-8, doi:10.1017/S0950268806007096 (2007).
11. Devchand, R. et al. Understanding consumer and clinician perceptions of a potential Lyme disease vaccine. *Health Educ Res* 36, 494-504, doi:10.1093/her/cyab032 (2022).
12. Hook, S. A. et al. Evaluating public acceptability of a potential Lyme disease vaccine using a population-based, cross-sectional survey in high incidence areas of the United States. *Vaccine* 40, 298-305, doi:10.1016/j.vaccine.2021.11.065 (2022).
13. World Health Organization. "Ten threats to global health in 2019. 2019." (2019).
14. Government of Canada, Innovation, Science and Economic Development Canada, Office of the Deputy Minister, Communications and Marketing Branch and Communications and Marketing Branch. "Roadmap for Open Science," February 25, 2020. <https://science.gc.ca/site/science/en/office-chief-science-advisor/open-science/roadmap-open-science>.