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### Case 9 : Managing Expectations: Lyme Disease

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## CASE 9

### Managing Expectations: Lyme Disease

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Dr. Kamal Karda arrived at her office Monday morning and was greeted with an urgent phone call from the Minister of Health. Newly appointed as the President of the Public Health Agency of Canada (PHAC), Dr. Karda had yet to settle into her new role. As she answered the phone, she could only imagine what information awaited her. Amongst her many priorities, she had been informed that Lyme disease would be a key component of the Minister's mandate and, as President of PHAC, Dr. Karda was expected to conduct a thorough analysis to formulate a plan on tackling the impact of and the issues surrounding Lyme disease in Canada. She was aware of the challenges surrounding Lyme disease and planned to draw on resources within the Agency to help shape her next course of action. She contemplated the roles of surveillance, policy, and communications as she gathered her thoughts. One thing was for certain: the margin of error was minimal to none. Her ability to formulate a plan would depend on strategic decision making, strong communication skills, and resourcefulness.

#### BACKGROUND

Lyme disease is a tick-borne zoonosis caused by *Borrelia burgdorferi* (Wormser, G. P. 2006). It has been known to illicit multisystem inflammatory disease symptoms. Rodents and ticks are the primary reservoirs of the disease. Lyme disease is primarily seen in the northern hemisphere and is the most commonly reported vector-borne disease in the United States, with an increase in cases being detected in Canada due to climate change. Lyme disease is characteristically known for a bullseye-shaped rash that appears at the bite site; however, this is not always the case.

The Public Health Agency of Canada (PHAC) engages in surveillance activity (PHAC, 2018). Of the many vector-borne diseases, Lyme disease has gained a significant amount of attention by the media in recent years due to rising incidences. Throughout the better part of two decades, various guidance documents have been formulated for Lyme disease as well as surveillance methods to help monitor the disease; however, minimal increases to funding have been granted. Currently, active surveillance is the primary way to gather data. However, in recent years, a push for passive surveillance has begun, due to the knowledge that many individuals who suffer from Lyme disease are not represented in the active surveillance data set.

Currently, PHAC relies on provincial governments to share data regarding confirmed cases of Lyme disease in order to track incidences and monitor trends. This form of active surveillance, while beneficial, has some pitfalls. Because of the unique clinical presentation of Lyme disease, it is not uncommon for some diagnoses to be missed, resulting in what patients and advocacy groups call "Chronic Lyme Disease." Chronic Lyme disease is believed to be a lingering, debilitating, clinical manifestation in patients who have been living with undiagnosed Lyme disease or Lyme disease that was diagnosed late in its clinical onset and thus, was not treated

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immediately. While there is no conclusive medical literature to solidify the existence of Chronic Lyme disease, there is a clear consensus on the use of antibiotic therapy upon immediate detection of Lyme disease. Therapy often consists of three readily available antibiotics: Doxycycline, Amoxicillin, and Cefuroxime (PHAC, 2017). The fact that many Canadians travel to the United States for diagnosis and treatment makes gathering the data required to inform policy and best practices even more problematic. There is a growing movement from those affected by the disease to garner more funding for acute care management. The belief surrounding this train of thought stems from the ideology that those suffering from Lyme disease do not have enough avenues for diagnosis, treatment, and rehabilitation.

To address the challenges of surveillance, analysts within PHAC tabled a proposal to create an online Lyme disease survey. The goal of the survey is to consolidate information from Canadian patients who have been diagnosed within and outside of Canada. The ability to create this form of passive data gathering, combined with existing active surveillance, would allow PHAC to use a larger, more comprehensive data set to aid in decision making. Guidance documents, such as the Canadian Lyme disease framework tabled in the early 2000s, emphasized surveillance and preventative interventions such as increasing awareness in provincial parks and educating health professionals to improve diagnosis and reporting. Evidence-based studies have not yielded the necessary data to indicate a drastic increase in funding for Lyme disease in regards to acute care, clinics, and altering current diagnostic testing. The current government has prioritized mental health and chronic disease prevention, and, as such, the majority of funding has been reserved for these causes. PHAC's role is to continue surveillance and provide guidance through best practices to the public as well as healthcare professionals in order to help in the management and detection of Lyme disease. PHAC does not have the ability to mandate regulatory initiatives and acts solely as a guidance agency for provincial governments in regards to Lyme disease.

The phone call from the Minister did not surprise Dr. Karda. In recent years, there had been increasing pressure from advocacy groups such as The Canadian Lyme Disease Foundation (CanLyme) to increase funding. CanLyme is a registered non-profit charitable organization that is run by volunteers throughout Canada (CanLyme, 2017). CanLyme advocates for better funding of acute care services for those currently infected with Lyme disease. CanLyme argues that funding should be allocated for improved treatment and more reliable diagnostic options, such as dedicated diagnostic testing sites, improved testing, specific Lyme clinics, and broader use of antibiotics. While PHAC has engaged CanLyme in discussions about these issues, in recent years, there has been resistance on the part of the advocacy group due to their perception of the federal government not responding. CanLyme states that it is dedicated to promoting research, education, diagnosis, and treatment of Lyme disease (CanLyme, 2017), which is also aligned with PHAC's goals. However, PHAC has put emphasis on prevention, maintaining that Lyme disease is entirely preventable, and, with the correct precautions, the incidences could be greatly reduced, if not eradicated. Dr. Karda understood the frustrations of the advocacy group but wanted to maintain the Agency's evidence-based approach to public health practice. Keeping an open line of communication with CanLyme would be integral to bridging the divide between the two points of view.

The Lyme disease unit is a part of the Centre for Food-borne, Environmental and Zoonotic Infectious Diseases at PHAC (CFEZID) (PHAC, 2017). Headed by Epidemiologist Justin Gera, the unit conducts Lyme disease surveillance and, over the course of two years, has hired additional staff to assist with the increasing workload. Funding within the government is often a key issue, and while the costs associated with Lyme disease were rising, the data analyses within the Lyme disease unit suggested that focusing on prevention would yield the highest net

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savings to the health care system. Preliminary analyses produced by Gera and the Lyme disease unit indicate that resource allocation towards prevention would result in the greatest impact on the health and wellbeing of Canadians, while also providing the most value for the funding allocated towards Lyme disease. Dr. Karda's top priority was allocating resources in an optimal way, aligned with evidence-based analysis.

While PHAC gathered information through surveillance and literature reviews, CanLyme garnered media attention and public support for Lyme disease funding. As the number of patients who suffered from Lyme disease increased, the ability to relay genuine heartfelt stories of those affected created a flurry of negative attention towards PHAC and highlighted the Agency's perceived inability to respond to calls for increased funding. Frustrations were beginning to rise on both sides, and within PHAC, media attention and pressure from CanLyme was creating conflicting ideologies with regards to the allocation of funds (preventative, treatment, testing, or a combination). Dr. Karda knew how crucial evidence-based public health principles were for bridging the gap between knowledge and application (Brownson, Fielding & Green, 2018).

Dr. Karda is tasked with garnering the support of her staff to deliver a unified message while supporting the Minister's mandate, acknowledging and addressing the advocacy group's concerns, and being fiscally responsible to the Canadian public. She must navigate the hurdles of building relationships with the various stakeholders (CanLyme, healthcare providers, public and patients, media, provincial governments, and PHAC employees) and exercising her leadership skills. Dr. Karda acknowledges the many systemic healthcare gaps and the natural frustration that accompanies delays in receiving care. As she continued to gather information for her analysis, she focused on maintaining an open dialogue with both the employees at PHAC and the patient advocacy group CanLyme.

Dr. Karda is now tasked with bridging the gap between her employees, the Minister, and the public's pressure and perception of PHAC's role and leadership in Lyme disease prevention and management. Precautions such as body checks after walking in high exposure areas are seen as the gold standard in early detection and treatment of Lyme disease and is an area that PHAC can promote to the public (PHAC, 2018). She also acknowledges that those suffering from Lyme disease rightfully would like answers that lead to immediate relief. There are more than adequate reserves for the antibiotics needed to treat Lyme disease, and there is no evidence indicating that creating Lyme-specific clinics would yield a change in incidences of the disease. Despite this, awareness and further education for healthcare providers seems like a logical step; however, there is no data currently available indicating the level of healthcare provider knowledge and ability to deal with the Lyme disease burden.

PHAC has a guidance relationship with the physicians of Canada but does not develop therapeutic protocols. It has traditionally provided information for patients and physicians alike. While new guidance documents are in the works, they are still months away from completion. Dr. Karda had asked for evidence-based documentation indicating the health outcomes and costs of Lyme disease in Canada, as well as supporting documentation from the United States, where there is more information available. She begins to synthesize the information and realizes that increasing funding for acute care management may not result in the best use of money for the overall healthcare system in Canada—a communication problem is the underlying issue. How will she, as President, ensure all parties involved truly understand PHAC's role in guidance? More so, she now has the opportunity to demonstrate to a large demographic PHAC's ability in monitoring and implementing public health initiatives that will have a lasting effect on the population of Canada.

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During the last governmental regime, PHAC's role had been diminished, and many employees within the organization as well as the public were anticipating positive change and forward momentum with the new government. Within the organization there is great hope and optimism amongst the different divisions for increased funding, allowing for further research, surveillance, outreach, and awareness. Dr. Karda seeks to temper the expectations of staff and an already skeptical advocacy group who doubted PHAC's course of action based on a disagreement about the priorities surrounding Lyme disease.

Based on the information provided, she realizes she has three options: 1) increase funding for Lyme disease in acute care settings based on the increase in incidences in Canada. This will allow her to dampen the push from CanLyme, gain added public support, and satisfy some of her staff; 2) increase funding for surveillance measures which will allow her to gather more accurate data so that she can later make recommendations based on a comprehensive data set and better advise the public, healthcare providers, and advocacy groups; or, 3) provide a marginal increase in funding for acute care measures such as medical education seminars for physicians while continuing to raise awareness in high risk parks and forests, all while indicating that additional funding for passive surveillance measures will help the Agency accumulate necessary data. Each option has its pros and cons and success will be based on how the message is framed and delivered.

Regardless of Dr. Karda's decision, it is imperative that she bridge the gap between the stakeholders and control the expectations of various parties. She must understand the positions of all parties involved while delivering on the Minister's mandate.

An interesting alternative would be to present options to the department heads in a brainstorming session. These approaches are vital to finding out-of-the-box solutions.

### CONCLUSION

PHAC provides leadership and guidance to all the provinces and territories as well as healthcare providers and citizens. PHAC is responsible for using evidence-based decision making to best protect and prevent against threats to health. PHAC has a chance to make a great impact with the new Liberal government in leadership. Responsible decision making and impactful guidance is of utmost importance at this pivotal time. Strong leadership and communication are crucial. True leadership entails assessing the various options, understanding processes, accounting for different viewpoints, and working collaboratively in order to attain a collective aim (Popescu G. H., Predescu, V. 2016).

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## INSTRUCTOR GUIDANCE

### Managing Expectations: Lyme Disease

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#### BACKGROUND

Increasing cases of Lyme disease are creating public outcry. The Public Health Agency of Canada (PHAC) has been tasked with the surveillance and guidance for this tick-borne disease but has not seen additional funding. Evidence-based analysis has indicated the most impactful use of resources would be spent on prevention and awareness. Despite this information, the push for increasing the healthcare budget to allow for more Lyme disease funding is growing. A desire to increase resources for acute care in the hopes of better diagnostic testing, more freely prescribed antibiotics, and dedicated Lyme clinics is being put forward from advocacy groups. As climate change worsens, Lyme incidences rising in the foreseeable future is probable. As the president of PHAC, managing different stakeholders within and outside of the organization while managing expectations is crucial. The ability to engage and inform while maintaining a positive public perception is key, as this will lay the framework for other initiatives to launch in the future. Balancing this delicate situation while maintaining an evidence-based approach will take caution and strategic skills.

#### OBJECTIVES

1. Decision-making thought process.
2. Discussion around prioritization of resources.
3. Leadership in difficult situations when there are no definitive right answers.

Creating competing interest groups will be beneficial in dividing the classroom for productive debate and conversation.

#### DISCUSSION QUESTIONS

1. Is it necessary to appease all parties?
2. How should one prioritize decisions?
3. When to discuss and when to decide?
4. Do we truly understand the issue at hand? Are the right parties involved?
5. What does the evidence indicate? What is our responsibility to the evidence gathered and what is our responsibility to the public in the immediate situation and the future?

#### KEYWORDS

Leadership; stakeholders; prioritization; evidence.