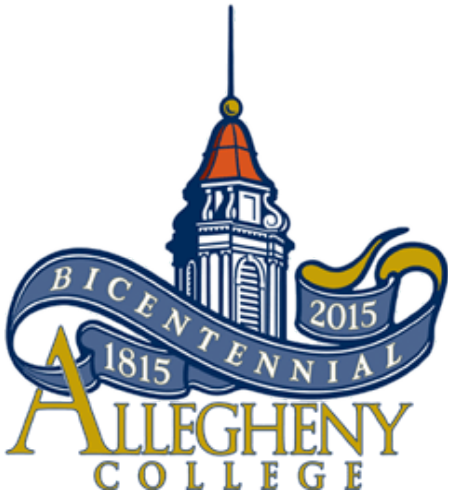
The relationship between Lyme disease risk perception and willingness to get vaccinated against Lyme disease:

Evidence from a KAP survey in Crawford County, Pennsylvania



Senior Comprehensive Project

in partial fulfillment of

Bachelor of Science Degree

Global Health Studies

April 2024

Alexis Furbush

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Alexis Furbush

This work represents my own work unless otherwise cited.

This senior comprehensive project has met the minimum requirements

of the Global Health Studies

major for a Bachelor of Sciences degree

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ABSTRACT

Name:	*Alexis Furbush*
Graduation Date:	*May 2024*
Title:	*The relationship between Lyme disease risk perception and willingness to get vaccinated against Lyme disease: Evidence from a KAP survey in Crawford County, Pennsylvania*
First Reader:	*Dr. Amelia B. Finaret*
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Pennsylvania reports one of the highest incidences of Lyme disease in the United States. This project measured the relationship between risk perception and vaccine hesitancy of Lyme disease in Crawford County, Pennsylvania. I developed a knowledge, attitude, and perception (KAP) survey to capture community awareness and attitudes toward Lyme disease and the likelihood of receiving a vaccine in a trial by Pfizer and Valneva. The literature contextualizes Lyme disease etiology, highlighting the vector-borne nature and the increasing incidence due to climate change, increased human-tick interactions, and other environmental challenges. By addressing these dynamics, these data provide a deeper understanding of health decision-making processes within rural communities, allowing for a thorough understanding of the risks associated with Lyme disease transmission within the Crawford County community.

In this rural region, there is decreased vaccine uptake in general, and attitudes towards a new vaccine are unknown. The survey was entirely anonymous and voluntary, participants were able to stop the survey at any time or skip questions. I designed the survey to capture the multiple factors influencing Lyme disease risk perception and vaccine hesitancy within a rural community context, with particular emphasis on the level of disease knowledge and reliance on information provided by healthcare systems. Obtaining 89 responses, the data indicated a disconnect between the perceived risk of Lyme disease and willingness to receive a vaccine; 44.9% of participants indicated the highest level of risk, and 33.7% indicated the highest likelihood of getting vaccinated. There was also a lack of awareness of the trial vaccine, 69.7% of participants had never heard of it, which further addresses the need for enhanced community education strategies. Public health is a growing field and the increased involvement in disease communications is highlighted throughout the literature, exploring challenges faced with mental health, politics, and healthcare relationships today.

In this case, effective public health interventions must address the distribution and control of Lyme disease and navigate the complex nature of vaccine hesitancy and risk perception. A major risk of Lyme is going undiagnosed, where the disease can attack central systems in the body. Communicating risk and prevention is crucial to ensuring timely diagnosis and protecting the community from the long-term effects of Lyme disease. Practical strategies include unique communication programs addressing vaccine hesitancy and building trust in healthcare institutions. By fostering informed decision-making and encouraging community engagement, efforts can be made to mitigate the burden of Lyme disease in endemic regions like Crawford County. Ultimately, this research emphasizes the importance of social approaches in mitigating Lyme disease risk amidst evolving environmental and societal challenges.

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Introduction and motivation

Lyme disease (borreliosis) is a vector-borne disease caused by the bacterium *Borrelia burgdorferi*. Lyme is the most commonly reported vector-borne disease in the United States (Eddens, et al., 2019). The bacterium is carried in the vector's midgut, the deer tick (*Ixodes scalpularis*) (Cornell, 2023). Ticks typically need to be attached to a host for 36-48 hours and take at least one blood meal to transfer the bacterium from the midgut of the deer tick to the bloodstream of the host; the tick will fall off the host once a blood meal is completed (Columbia, 2018). There are four stages in the two-year life cycle of a deer tick. Starting from an egg, once a tick hatches it will take up to three blood meals in its life; once during the 6-legged larval stage, another in the 8-legged nymph stage, and typically one more once it grows into an adult male or female tick (Brownstein, et al., 2005). Only nymph and adult ticks can transmit the Lyme pathogen (Bouchard, et al., 2019).

A tick can carry the bacterium and transfer it to hosts, but it does not naturally occur in ticks. The most common hosts are white-tailed deer, small mammals like the white-footed field mouse, rats, and humans (Brewer, et al., 2004). Lyme is often picked up by ticks from a small mammal because white-tailed deer do not carry the Lyme bacterium, their purpose in the tick life-cycle is a commensal organism where a tick attaches to the outer surfaces of the body and feeds off of the internal environment of the host without harming it (Khan, et al., 2019, CDC, 2023). The deer tick can survive around 24-72 hours without a host, a tick that has fed once will typically survive longer without a host than one who has not taken a blood meal (Brownstein, et al., 2005). Symptoms of Lyme disease (Lyme) can present mildly in the body and go unnoticed, with or without the presence of the most alarming erythema migrans (EM) typically referred to as a “bullseye” shaped rash on the skin; or the bacterium can travel to joints, cardiac and nervous systems and cause much larger issues to the host (Hook, et al., 2022).

Lyme is an emerging threat to populations worldwide, especially with an increase in climate change, which has increased the overall number of ticks in an area due to increasing temperatures and humidity; making it an easier place for ticks to survive and not die off in the colder temperatures or dry air (Thomson & Stanberry, 2022). Deer ticks are typically less active in consistently cold temperatures. When temperatures drop below 35℉-45℉, ticks become dormant, and do not move around as they would in warmer temperatures, while still present in the area and able to attach to a host (Korenberg, 2022). Lyme incidence is increasing rapidly in regions where it is endemic, like Northwestern (NW) Pennsylvania, because it is common to have temperatures above 35℉-45℉, which makes it possible for ticks to attach to a host (human) if they are spending time outside (Wozinska, et al., 2022).

To be considered a "rural community" there must be less than 291 residents per square mile in the county, municipal, or school district within the county (Center for Rural PA, 2020). Crawford County is among 48 rural counties in Pennsylvania, with 88 residents per square mile in the measured regions (FORHP, 2021, US Census Bureau, 2021). Pennsylvania reports more total Lyme cases per year than any other US state, and about 30% of deer ticks carry the bacterium (Pennsylvania Department of Health). In more rural areas, like Crawford and Mercer counties, people who spend a lot of time outside or have indoor pets that go outside are not strangers to the risk of Lyme, but they might not entirely know how to protect themselves or what to look for if they have been bitten by a tick - or know what kind of tick has become attached (Chester County Health Department, 2022). Lyme cases in rural zip codes more often progress to cranial nerve (CN) palsy and joint swelling than in urban zip codes due to knowledge of the risks of undiagnosed Lyme, and access to healthcare providers (Eddens, et al., 2019).

Public health and Lyme disease

Public health efforts can be made to increase knowledge of Lyme and ensure it is diagnosed correctly and quickly to prevent symptoms from spreading through the body and causing long-term health complications (Beaujean, et al., 2013). Lyme disease as an emerging public health threat requires many efforts to mitigate risks to people living in high-risk areas. High-risk involves those who spend a lot of time outdoors, live near or frequent tall grass or wooded areas, and have indoor pets that go outside (Beaujean, et al., 2013). NW Pennsylvania has seen a large uptake in Lyme cases, due to increased human-tick contact with the popularization of living more active outdoor lifestyles, an increase in outdoor sports, and extended warm temperatures that keep humans and ticks active longer (Wozinska, et al., 2022).

The rise in Lyme cases in Pennsylvania can also be attributed to the large population of white-tailed deer, which are a significant host during the adult stages of the deer tick and can carry many ticks at one time, which expands their range, as deer travel frequently (Thompson & Stanberry, 2023). Lack of knowledge, insufficient education on preventative measures, and an increasing number of ticks are collectively contributing to the rise in cases (Throckmorton-Hansford, 2023). An increase in Lyme disease research creates new realms of public health responsibilities to properly inform citizens of what is going on in their communities and how to protect themselves against a tick-borne illness and know what to do if they become infected.

The importance of cost-effective solutions and interventions is to ensure resources are going where they are needed and would be accepted by the target populations (Greig, et al., 2018). Vaccine programs, prevention communication, and self-accessible information can improve the comprehension of risks associated with Lyme disease (Martinelli and Veltri, 2021). A Valneva and Pfizer vaccine for Lyme is

currently in trial, using a similar structure as the previous vaccine. A three-dose “LYMErix” vaccine was made available to the public in 1998 by SmithKline Beecham, which decreased Lyme rates by 76% among people who received the vaccine (Boyle, 2022). However, the vaccine was taken off of the market four years later in 2002 after accusations of arthritis appearing in those vaccinated and the public did not favor the vaccine, as it required three doses to be effective, (Pine, et al., 2023).

A new vaccine can potentially lessen the severity and spread of Lyme disease with improved science and technology (Clinical Infectious Disease, vol 52., 2011). The proteins in *Borrelia burgdorferi* are promising to be a target for a vaccine that has the potential to be effective against Lyme and other strains of tick-borne diseases (Pine, et al., 2022). Even with new technology, and bacteria susceptible to a vaccine, the introduction of any new vaccine or medicine can cause individuals to be skeptical, or vaccine-hesitant (Wang, et al., 2022).

Vaccine hesitancy

Vaccine hesitancy is the refusal to receive a vaccine despite the availability of the vaccine and sufficient research on effectiveness (MacDonald, et al., 2015). Refusal of a potentially very effective vaccine to treat an emerging threat has partly come from the increase of consumerism in the US healthcare system with readily available ‘super drugs’ or organic supplements that have steered many away from allopathic medicine, and individuals are becoming more critical in making decisions regarding their health (Dubé, et al., 2013). Understanding why people make health decisions, what background they are coming from, and the experiences they have had are important parts of understanding vaccine hesitancy, as well as how to handle emerging diseases in the public health sector (Dubé, et al., 2013).

Vaccine hesitancy is inherently a social interaction because the choice is made based on morals and beliefs. After all, most vaccines are supported based on contributing to the health of the rest of the population (in this case the Lyme vaccine does not create herd immunity) (Brewer, et al., 2017). Herd immunity is the protection of a population against an infectious disease through the immunity of the majority of individuals in the population, either through antibodies from previous infection or a vaccine (Ashby and Best, 2021). This form of protection, to an extent, lessens the spread of infectious disease and protects individuals who are immunocompromised, unable to get vaccinated, or vaccine-hesitant. Individuals typically receive vaccinations from their healthcare providers or their regular offices, making the relationship and trust between patients and providers a large factor in exploring vaccine hesitancy (Brewer, et al., 2017).

A trial vaccine created by Pfizer and Valneva uses a “lipid nanoparticle-encapsulated nucleoside-modified mRNA (mRNA-LNP)” vaccine, which is similar to the previous LYMErix vaccine as well as the Pfizer vaccine for COVID-19 (PudMed, 2023). Researchers are optimistic that one of the surface proteins of Lyme is a promising antigen to be vaccine-effective (Pine, et al., 2023). An “OspA-encoding mRna-LNP vaccine” was created and compared to a subunit vaccine to test its efficacy which showed prominent immune responses in mice after a single dose, protecting the mammal against bacterial infection (Pfizer, 2023). If the vaccine could prove effective to the mice via oral ingestion, this would significantly reduce the number of ticks carrying the bacterium, decreasing human infection (Pennsylvania Tick Lab, 2023). The increase in Lyme cases in regions where Lyme is endemic fuels the new research taking place, as well as creating new vaccines, better educating health officials and communities on identification and treatment, and increasing awareness of the consequences of untreated Lyme disease (Dumic, et al., 2018).

Moving forward

This project will use a three-chapter module to identify public health effectiveness in communicating Lyme risk and build on the work of the Pennsylvania Tick Lab Lyme research conducted thus far, by analyzing data from a knowledge, attitude, and perception (KAP) survey administered to residents in Crawford County, Pennsylvania via flyers distributed to several local businesses and the local "FYI Crawford County" Facebook page. KAP surveys are effective in identifying how well communication networks are delivering information and assessing how the information is received by the public (Goutille, et al., 2009). A strength of this KAP survey is that it estimated awareness of Lyme disease among the general public with no indication of education level, age, or occupation; the survey effectively captured a broad spectrum of the population's awareness of Lyme disease, providing a better gauge of public knowledge. Including different demographic groups, the survey results are more reliable and applicable to the broader population, increasing the validity and generalizability of the responses.

The questions in the survey were designed to make participants recall what they know about Lyme disease, and how they interact with the possibility or presence of the disease in their own lives. To encourage participants to further educate themselves on the signs and risks associated with Lyme disease, there is a link to the Centers for Disease and Prevention (CDC) webpage for Lyme disease at the end of the survey to provide direct access to more information.

89 responses were collected from the survey from December to January. The data showed that on a 1-5 scale, 5 meaning most likely, 44.9% of respondents believed they were at a high-risk of getting Lyme disease. Less than half of the sample, 33.7% indicated on the same scale that they would be very likely to receive a Lyme vaccine if one became available. Of those concerned about getting Lyme disease, the likeliness to get the vaccine is about 10% lower. Only 30.3% of the sample have heard of the vaccine in

the trial, which supports the 78.4% of respondents who indicated more information needs to be provided to the community about the increasing incidence of Lyme disease.

Navigating the Lyme light; background and vaccine hesitancy

Lyme can present itself in the body in several different ways. Symptoms of Lyme can originate as a "bullseye" shaped rash, fever, fatigue, joint pain, and headache. The typical bullseye rash around the tick bite is not always present on human skin, which makes the diagnosis or level of concern difficult to gauge (Hook, et al., 2022). If the bacterium spreads throughout the body without treatment, it can spread the pain and infection to the nervous system and heart (Dumic, et al., 2018). These symptoms can be easily attributed to the common cold, or other illnesses before people suspect they have Lyme. If the tick is still attached and is unengorged (flat) that could indicate the tick was not attached to the host long enough to complete a blood meal and transfer the bacterium, but symptoms should still be monitored (Estrada-Peña, et al., 2017). If the attached tick is engorged (round) or has changed in color to brown or red, the tick should be carefully removed by an experienced individual and sent for testing, or seek medical attention to be removed by a professional and test the human host (Estrada-Peña, et al., 2017).

There is a disconnect between the importance of seeking medical attention, and not having access to it (Omaduvie, et al., 2021). Attitudes towards or access to healthcare are important in thinking about emerging diseases and new methods of prevention, like vaccines. It is most common that a person will receive a vaccine from their healthcare provider, this suggests a level of trust and understanding in making the decision to get the vaccine as well as trusting the provider to administer it (Cao, et al., 2022). Suppose an individual has distrust in the healthcare system or feels like they are not properly represented in that setting. In that case, they are very unlikely to trust information coming from a provider (McNeil-Willson, 2020). If an individual does not trust their healthcare provider and does not feel at risk of a disease, they are very unlikely to receive a vaccine, and would not be likely to be

influenced by an increase in knowledge or recommendations from a healthcare professional (Hook, et al., 2022).

Healthcare involvement and public health prevention

One cause of the significant increase in Lyme cases in NW Pennsylvania is due to medical professionals having a better understanding of the risk and incidence of Lyme disease in the area, knowing what signs and symptoms to look for in a patient, and testing if they are at all concerned that Lyme might be present (Wozinksa, et al., 2022). In the past, many cases of Lyme would progress dangerously because providers were not aware of the symptoms, or the incidence of Lyme in the area (Radolf, et al., 2021). Increased provider knowledge allows providers to relay the information to their patients who are living in areas with a higher risk of Lyme, with information coming from a trusted source (Martinelli and Veltri, 2021). Lyme prevention is largely based on the individual. Due to the severity of the disease going undiagnosed, especially in immunocompromised people, another preventative measure would be a vaccine against the disease (Kreidl, et al., 2017). If Lyme is undiagnosed, it can cause post-Lyme disease syndrome, CN palsy, facial paralysis, cardiac arrhythmia, or Lyme neuroborreliosis (LNB), severe swelling of the brain and spine (Ścieszka, et al., 2015, Eddens, et al., 2019). While you cannot force people to implement safety precautions, you can educate them enough to understand their risks (Quinn, et al., 2021).

Managing any emerging disease can be difficult in the public health sector. Disease education and communicating preventative measures are crucial strategies to start the conversation about the risk of Lyme (Throckmorton-Hansford, 2023). Preventative behaviors are used based on the perception of risk (Hansen, et al., 2021). To be best protected, the public needs to understand who is at risk and where Lyme disease comes from. Most often, people living in rural areas have a higher perception of risk; as

well as people who have compromised health, or know someone who has been diagnosed with Lyme (Brewer, et al., 2004). People in good health, individuals living in urban areas, and of a younger age often have a decreased risk perception of Lyme (Foguel and Chawla, 2017).

If a tick bites someone, they should know how to identify the species of the tick, what symptoms to look for, what to do with the tick, and when to seek medical treatment (Pennsylvania Tick Lab, 2023). Communities can implement land management strategies, temperature-based warning systems, insecticide (permethrin) treatment in public areas, and improved access to preventative measures like vaccines, personal preventative measures, full-coverage clothing, and insect deterrents (Thompson and Stanberry, 2022). Individuals can only completely prevent contact with ticks by not going outside, but it is nearly impossible to never go outside again. Any interaction outdoors in an area of dense tick population could bring the risk of contact with a tick.

The most attainable and effective insect/tick repellants are those that contain the insect repellant N, N-Diethyl-3-methylbenzamide (DEET), however, most people assume DEET is unsafe to use and would rather avoid minimal dermal exposure and risk getting Lyme (Haleem, et al., 2020). Communities expressed concern during the 1980s that encephalopathy (diseases in the brain that alter the function or structure entirely) occurred after DEET exposure, particularly prevalent in children (Chen-Hussey, et al., 2014). The claims were studied extensively and when used in appropriate settings and doses, there are no adverse effects in animals or humans (Chen-Husset, et al., 2014). This leverage of risk regarding DEET as an insect repellant was measured through a survey, where 77% of people who purchased a repellent in the last year, chose one advertised as ‘all natural’ or not containing DEET (Wozinska, et al., 2022). If people do not know they are at risk of Lyme, they will not exercise preventative measures properly (Wozinska, et al., 2022).

An increased perception of risk is associated with an increase in preventative behaviors, as preventative measures for Lyme are personal choices based on the clothes a person wears, and their behaviors after spending time outside. The mindset of an individual plays a crucial role in understanding the threat of an emerging disease and exercising preventative measures; if people are more intuitive or optimistic, they are more likely to participate in measures to prevent or lessen the severity of a disease (Martinelli and Veltri, 2021).

Health, politics, & attitudes

Unfortunately, optimism is not the typical public response to an emerging disease. A large part of this project was assessing the attitude of participants regarding their knowledge and acceptance of a potential vaccine, and exploring vaccine hesitancy in a rural community in NW Pennsylvania. Following the COVID-19 pandemic in 2020, worldwide, more people are vaccine-hesitant than ever before, because many believe vaccines are unsafe and over-politicized, assuming every vaccine opportunity will be mandated as a 'way to control the public' (Lathrop, et al., 2002). Living post-pandemic has created a lot of fear and frustration surrounding emerging diseases, and has brought a lot of distrust in the government and public health sector (Mehta, et al., 2022).

Many people are hesitant about vaccines, thus creating a lot of fear and anxiety when a new vaccine is introduced to the public. To receive a vaccine requires a certain level of knowledge of the disease and its risks, knowledge of the vaccine, and trust in information coming from public officials (Shen, et al., 2011). While a Lyme vaccine is completely optional, and for personal protection only, a vaccine that enters the tick via the host during a blood meal and kills the bacterium would reduce the spread of Lyme and the number of infected ticks (Thanassi and Schoen, 2000). This lack of trust in vaccines and health officials

puts vaccination programs at a high-risk of decreased coverage, and disease outbreaks that could otherwise be preventable through vaccination (Dubé, et al., 2013).

Attitudes toward healthcare are important to consider when thinking about emerging diseases and new vaccines. If an individual has distrust in the healthcare system and does not feel at risk of a disease, they are highly unlikely to get a vaccine, and would not be influenced by an increase in knowledge or recommendations from a healthcare professional (Hook, et al., 2022). A previous KAP survey of tick-borne disease awareness showed that even with low awareness of the risk of Lyme, respondents had positive attitudes towards a potential vaccine and would consider getting vaccinated if it became available to them (Wozinska, et al., 2022). There are numerous factors in making any health decision, especially when it comes to vaccination.

Cultural and personal beliefs, political opinions, past experiences, and social perspectives all play significant roles in determining vaccine uptake (Dubé, et al., 2013). Public health officials should thoroughly comprehend these contexts to effectively address vaccine challenges (Bouchard, et al., 2018). Vaccine hesitancy can profoundly impact mental health and exacerbate health and social anxiety during the decision-making process regarding vaccination, especially when there is a perceived societal moral obligation associated with achieving herd immunity (Quinn, et al., 2021). Communicating risk and implementing prevention programs are crucial strategies for mitigating the spread of Lyme disease, but needs to be done from a point of security in the information being translated (Goldstein, et al., 2015).

Past, present, and potential research

Recently, research has been conducted by the Pennsylvania Tick Lab at East Stroudsburg University to gain a better understanding of how to mitigate the increasing number of ticks in the area through vegetation surveys and data collected from live-captured white-footed mice to measure trends in tick activity (Pennsylvania Tick Lab, 2023). The mice are significant in the transmission of Lyme because as tick presence is expanding, the white-footed mouse is also expanding its range north due to winters becoming milder (Simon, et al., 2014). Additionally, the Lab is working to test the effectiveness of vaccinating mice with the trial oral mRNA-LNP vaccine to protect the mice and reduce the number of ticks, and tick-borne diseases before they occur rather than treating existing cases (Pennsylvania Tick Lab, 2023). Vaccinating mice with the oral vaccine is crucial because ticks do not carry the bacterium responsible for Lyme disease until they feed on an infected host.

By vaccinating the main hosts, transmission of Lyme disease to the ticks is reduced, by potentially killing existing ticks attached to the mammal (Haleem, et al., 2020). A larval tick is most likely to feed on a small rodent, like the white-footed mouse, as its first meal in the first stage of their life cycle; if the host mouse carries the Lyme bacterium, that meal will transmit Lyme to the tick early in life and carried into the next life stage (Simon, et al., 2014). This research is vital for NW Pennsylvania because the rising tick population heightens the risk of Lyme for residents, who currently lack effective solutions beyond personal preventative measures.

I hypothesized the survey responses would indicate if participants falsely perceive a low risk of Lyme, they may also express a lack of need for a vaccine, which is contradictory to the true risk level in the area and would support the lack of information provided to the general public. Alternatively, participants may acknowledge the high risk of Lyme but still indicate a small likelihood of getting vaccinated, which could

insinuate vaccine hesitancy (Hansen, et al., 2021). These data are important in prompting individuals in an area with an overall high-risk of Lyme to identify where improvements in public health can be made, as well as the receptiveness to a potential vaccine (Bouchard, et al., 2018). Following a pandemic and the condition of political communications, individuals are more likely now than ever to question science and the legitimacy of information being given to them (Hook, et al., 2022).

KAP surveys can effectively identify how well communication networks deliver information and gauge how public officials or healthcare providers can contribute to prevention programs that reach the target audience (Goutille, et al., 2009). With the trial vaccine, people are concerned about the politics that followed the COVID-19 vaccine and are hesitant to take a vaccine if they do not think they necessarily need it (Herrington, 2004). With the risks of Lyme disease going undiagnosed and the bacterium spreading through the body, there are many different strategies to use when educating the public on how to protect themselves. Informing communities of strategies that healthcare providers and public officials plan to implement or how important the prevention of Lyme is to the surrounding areas can keep the communication transparent and keep the community informed and feel as though they have a space in the discussion (Wang, et al., 2022).

Unraveling the Threads

Methods

Securely collecting information regarding health-related behaviors or health-seeking behaviors was crucial to maintaining the integrity of this research and keeping participants as comfortable and informed as possible. KAP surveys are commonly used in assessing health-related behaviors and are an effective way to obtain general information regarding disease knowledge and risk perception (Launiala, 2009). If individuals do not know they are at a high risk of disease or understand that some populations are at a higher risk than others they will not take preventative measures to protect themselves (Wang, et al., 2022). With diseases like Lyme, prevention solely relies on individual behaviors. The KAP survey distributed for this project included a series of questions (Appendix I) to determine if participants felt at risk of Lyme, and whether or not they would be vaccinated against Lyme if it were available to them; assessing risk perception and vaccine willingness to determine disease knowledge and presence of vaccine hesitancy.

Whether or not the trial vaccine makes it to market, public awareness of the oral vaccine research for small mammals is important as it helps to comprehend how the risk could diminish with the delivery of this method (O'Mara-Eves, et al., 2015). At the end of the survey, Lyme disease information by the CDC was included as it would be a disservice to all survey participants if more information was not provided. In the global and public health context, a significant goal is to provide clear and accurate information to the general public when attempting to collect data based on the participant's level of knowledge, rather than asking a series of questions and moving forward (Goutille, et al., 2009). This ensured that an effort was made to better inform participants about the risks of Lyme and ways to prevent the disease should the survey spark further interest. To further support this distribution of information and assess the public

outreach, the survey asks participants to indicate if more information should be provided regarding Lyme, and from whom.

To meet the aims of the study and assess knowledge, attitude, and perception of Lyme disease and a trial Lyme vaccine, a survey created through Google Forms was distributed electronically and in several businesses in the Crawford County area. The survey was taken online and the link was available via a scannable QR code to Crawford County residents attending several high-traffic outdoor stores in Meadville, PA. Tops, Tractor Supply, Meadville Farm and Family, and The Boot Box allowed, with written permission, the flyer to be posted in the business. The survey was available on Facebook on the local "FYI Crawford County" page. Questions were created using Floyd J. Fowler Jr's "Survey Research Methods" to gauge participants' perception of risk based on location and outdoor contact, home pets, and preventative measures to compare against willingness to be vaccinated. Using Fowler's method supported the efficacy of the questions being asked, as well as collecting data in the most ethical and respectful ways. No identifiable information was collected from participants, and the survey was voluntary, participants could choose at any time to not continue; the only requirement of participants was confirmation that they were above the age of 18.

The data from the KAP survey compared how risk management, perception of risk, and vaccine hesitancy contribute to the increased incidence of Lyme disease, and how the public perceives the risk of tick-borne illnesses and the potential of a vaccine to reduce that risk. There is a gap in public knowledge of Lyme and a need for community leaders in the surrounding area to improve communication efforts to translate the risks and dangers of Lyme disease.

Approval was required and obtained from the Allegheny College Institutional Review Board (IRB) to distribute the survey. This committee is required at all research institutions to monitor research involving human subjects and to ensure all research practices are done in a manner that protects human rights and welfare (Allegheny College). To obtain approval, I was required to submit all documents describing the study, which included survey questions, potential graphics used to advertise, as well as proof of the CITI certifications to conduct research mandatory for myself and my advisors in the department. This process was beneficial in preparing the survey for myself as a researcher and for all participants to have the best outcome.

I opted for the survey to be completed online because in-person interviews concerning health, disease, or public practices might only be socially desirable for some participants, which would affect the way they respond (Fowler, 1984). This gave participants the ability to comfortably answer questions without confrontation and at their own time and pace. The survey included 8 close-ended questions and 1 open-ended question (Appendix I) regarding how much they know about Lyme, whether or not they think they are among a high-risk population, if they implement preventative measures in their own lives, and if they would get a Lyme vaccine should one be made available. Participants were provided with a copy of the informed consent, and a brief overview of the purpose and contents of the project.

Results

89 responses were obtained from December to February. Despite living in an area with the highest reported cases of Lyme per 100,000 people (Chinnici, 2023), 44.9% of respondents indicated they were at a level 5 of likeliness or risk to get Lyme disease on a 1-5 scale (Figure 1), 1 being least likely and 5 most likely. This could be a result of the respondents living closer to the downtown area of Meadville or do not spend a lot of time outdoors. However, only 4.5% of respondents answered < 3, so there is some

perception of risk in the area. To highlight risk factors, participants were asked if they had an indoor pet that went outside, 88 participants responded to this, and 68.2% did have an indoor pet that goes outside, which increases their risk. When asked to choose the best personal prevention against Lyme, out of the 4 options given, 88.7% selected the (correct) option that included using insect repellent containing DEET (Figure 2).

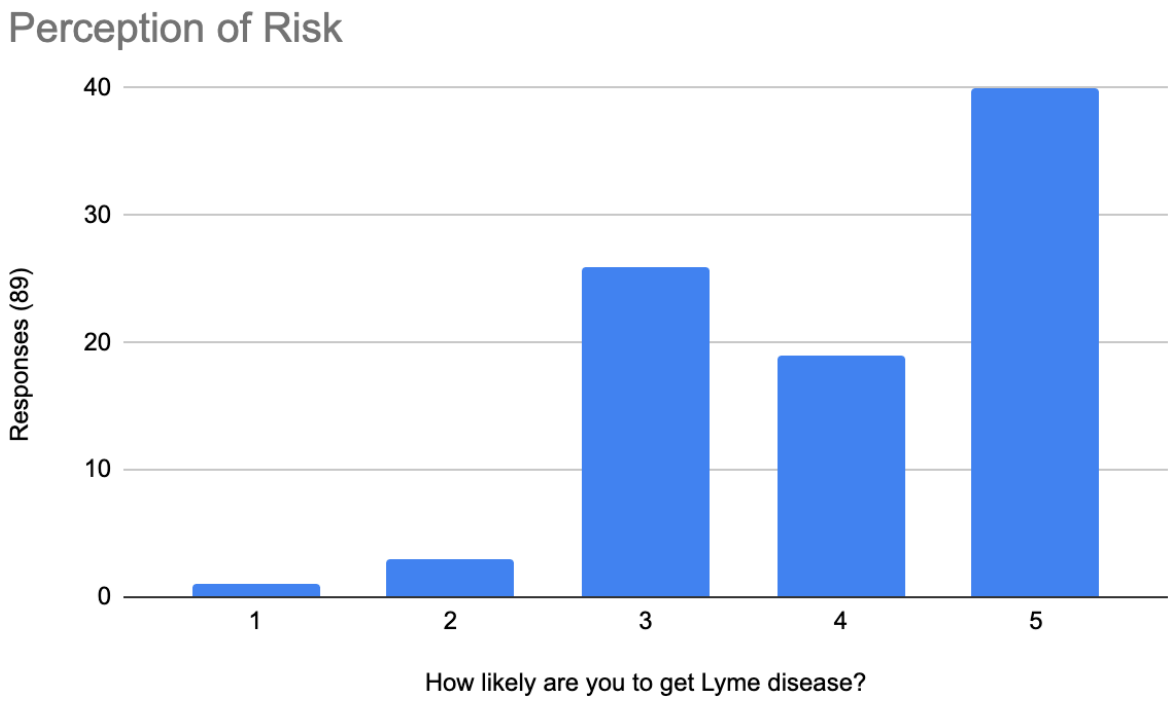


Figure 1: Perception of risk for Lyme disease

1 - Least likely

5 - Most likely

Source: KAP survey results

To assess the need for more information and obtain an unbiased answer to where the general public gets their information from, and whom they want more from; participants were asked first if they thought more could be done to inform citizens about the increasing number of ticks in the area followed by 4

choices of whom they want to hear that information from. Out of 88 responses to this question, 78.4% answered 'yes' to agree that more could be done to inform the public and 17% answered that they did not know (Figure 3). 57.3% of the 89 respondents indicated wanting to hear more information from medical professionals among 3 other options including local government (county) representatives, individual town representatives, and self-accessible information.

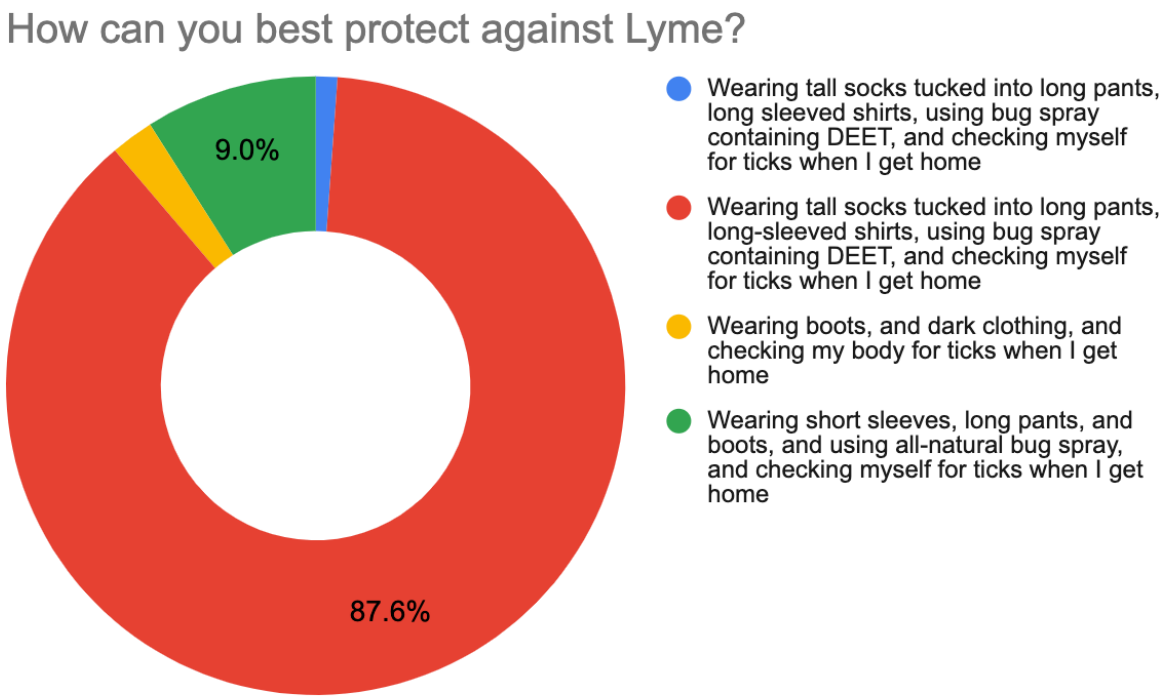


Figure 2: Best protection method for Lyme

Source: KAP survey results

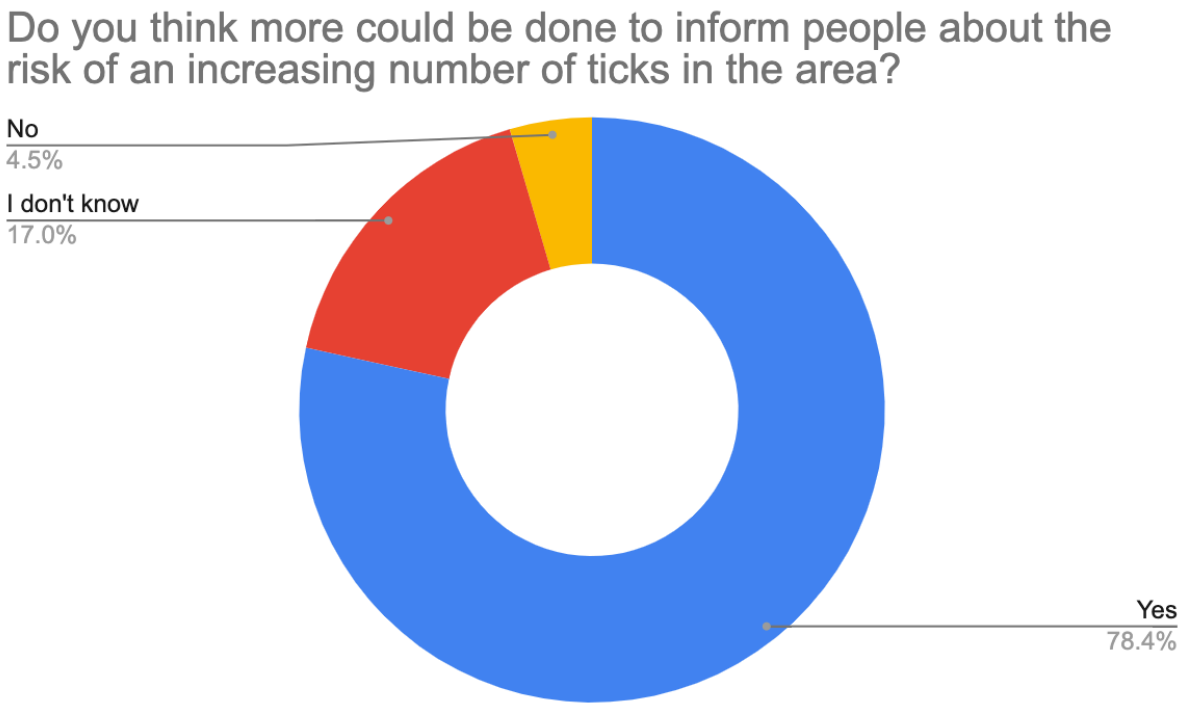


Figure 3: Could more be done to inform people about the risk of an increasing number of ticks?

Source: KAP Survey Results

Two questions were asked about the (Pfizer and Valneva) trial Lyme disease vaccine. The first is simply that if the respondent has heard of the vaccine, 69.7% answered 'no' that they have not heard of the vaccine currently in trial. Of all responses, 33.7% selected 5 on a 1-5 scale of likeliness, 5 meaning most likely, to get vaccinated against Lyme disease if the vaccine became available (Figure 4). 21.3% were not at all likely to receive the vaccine if given the opportunity. Participants were also asked if they or anyone (pets or humans) living in the home has been diagnosed with Lyme in the past year, as this could also gauge willingness to get vaccinated, 67.4% answered 'no'. If they have not had Lyme or know someone closely who had Lyme, they might not be aware of the severity of the disease, therefore not understanding the importance of a Lyme vaccine.

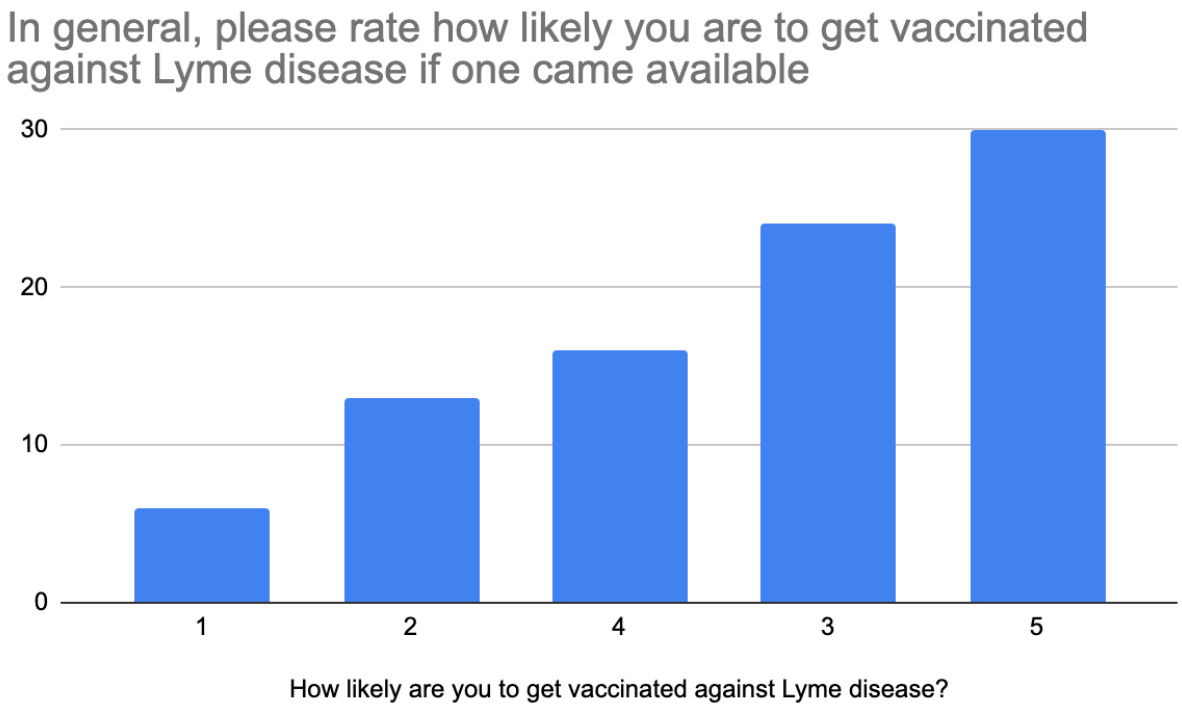


Figure 4: Willingness to get vaccinated against Lyme disease

1 - Least likely

5 - Most likely

Source: KAP survey results

Of the 89 survey participants, 79 answered the qualitative question 'How do you prevent or reduce your risk of Lyme?'. 24 responses indicated using insect spray on themselves, their animals, and/or their yards. 20 answers included the type of full-coverage clothing they wear outside, including long socks and boots, long pants, and long-sleeved shirts. 2 participants shared that their dogs were vaccinated against Lyme, and 1 participant was enrolled in the Pfizer and Valneva vaccine trial. 49 responses stressed the importance of extensively checking themselves, their pets, and their children for ticks after being outdoors at any time. 2 participants included 'awareness' in their responses, being aware of the

symptoms and the risk, and making a point to raise awareness due to their experience with the disease and test frequently if symptoms arise.

Ticks, Temperature, and Trouble

Discussion

Only three survey questions had fewer answers than the total number of responses. Two questions had 88 responses, which were if the respondent thought more could be done about the increasing number of ticks in the area and if they had an indoor pet that goes outside. The qualitative question 'How do (you) prevent or reduce (your) risk of Lyme?' received 79 responses. The decline in responses to the qualitative question could be due to not knowing how they prevent Lyme, not doing anything to intentionally prevent it, or simply not wanting to type out a long answer. Participants could have skipped the pet question if they did not have one or thought it did not apply to them because they did not have one. If a participant did not have an opinion or did not know how to answer when asked if more could be done to inform the community, this could be an explanation for skipping that question.

One limitation is that the survey is susceptible to human error, as well as being completely voluntary, participants could skip any question they wished after the age verification. The small percentage of respondents who are very likely to get vaccinated if one became available (Figure 4) compared to the large percentage of respondents who have not heard of the vaccine at all could explain the need for more information about the research being conducted in the area, as well as needing more information surrounding the increase in ticks and Lyme cases in general. The program used to create Figure 4 organized the data out of numerical order but with correct visual representation, 27% of participants selected 3 and 18% selected 4.

The only data that represented sufficient public knowledge was 'How can you best prevent against Lyme?' (Figure 2). The Google program used to create the graph included two sections for this answer, but combined a total of 88.7% of respondents selected the DEET option. The large percentage of

responses that correctly selected the option that included DEET shows that there is some level of knowledge on Lyme prevention, however; there was only one option that included the insecticide. Selecting this option could be representative of Lyme understanding, but there is bias present if using 'DEET' as a term in only one option influenced a participant to select that option.

The purpose of this KAP survey was to gauge public perception, knowledge, and willingness to get vaccinated for Lyme. A large contributor to the increased incidence of Lyme disease is climate change (Dumic and Severnini, 2018). The survey intentionally omitted questions concerning climate change or environmental processes to prevent interference with recalling disease knowledge and vaccine attitudes. This precaution was taken because participants with strong opinions about climate change might associate the survey with discussions about climate change rather than focusing on the impact of Lyme disease. Inquiring the general public for information or opinions on vaccine uptake could already be personal, and I intended to keep the survey brief and only ask for the information needed. In my opinion and experience in working with the public, climate change can be a political conversation, and also holds the potential to lead to a negative response to the survey entirely; keeping the focus on Lyme and public outreach was important to me in this instance.

Climate change and Lyme disease

The increased incidence and geographical spread of Lyme disease is largely due to climate change and increased levels of greenhouse gas emissions (Monaghan, et al., 2015). Lyme disease is a clear example of the connection between environmental factors and vector-borne diseases due to the ease of vector survival and frequency of transmission to various hosts (Dumic and Severnini, 2018). With mild winters continuing and projected to increase minimum temperatures, vectors and hosts are expanding to the

northern parts of the United States, and into Canada where Lyme has not been a significant risk before (Brownstein, et al., 2005).

An increase in temperatures and humidity where Lyme is endemic has shown a dramatic spike in cases, for example, in 1991, The United States reported about 10,000 cases per year whereas almost 30,000 cases were reported in 2023 (Dumic and Severnini, 2018). 30,000 is only the reported number of cases, though the CDC uses insurance records to estimate that over 476,000 people are diagnosed with Lyme disease per year (CDC, 2023). While there could be other environmental factors contributing to the increase in Lyme cases, cases are occurring outside of the typical seasons that Lyme is present, and this variation in annual diagnoses aligns with record temperature increases during those times (Couper, et al., 2021).

North America is not the only region experiencing increased intensity of vector-borne diseases. Other vector-borne diseases, like malaria and dengue, have increased in transmission in other regions of the world (Brownstein, et al., 2005). Tick-borne encephalitis (TBE) is a viral infection that is carried by a small number of ticks, mainly in species found in Europe, Russia, and Asia; but climate change poses the risk of increasing where this virus is geographically (Süss, 2002). An increase in global temperatures raises concerns about any vector-borne disease, but Lyme disease is occurring more frequently all over the world. In North America, Lyme cases are decreasing in the south, and increasing rapidly in the northern regions earlier in the year because ticks can survive in the habitats emerging, as well as long periods of increased humidity and minimum temperatures (Brownstein, et al., 2005).

Ticks thrive in moist, humid, and warm environments surrounded by tall grasses, trees, or leaf litters low to the ground (Eddens, et al., 2019). It takes about 36-48 hours for a deer tick to complete a blood meal

and transfer the Lyme bacterium to the host and symptoms of Lyme could take as long as 3-5 weeks to present in the body (Dumic and Severnini, 2018). During this time, without a vaccine or knowledge of the tick bite on the body, Lyme can migrate and manifest in large systems in the body to further complicate the treatment and symptom identification.

It is projected that by the 2060s Lyme disease cases and the overall number of ticks will increase by 213% in Canada, and the annual onset of Lyme will occur 0.5-3.5 weeks earlier in northern parts of the United States (Monaghan, et al., 2015). Higher levels of spring precipitation and humidity have increased transmission, the intensity of Lyme, and the overall number of ticks because when warmer temperatures are observed earlier in the year than normal for a region, female adult ticks mate and lay eggs earlier (Simon, et al., 2014). This will lead to ticks hatching and beginning their life cycle stages of active larvae and nymphs during the months when transmission is normally reported as high (Süss, 2002).

Female adult deer ticks will mate with a male attached to the same host typically after the male completes a blood meal. The female will fall off the host after its blood meal and mating is complete, 2,000-6,000 eggs will be laid and hatch after 9-60 days (Brownstein, et al., 2005). A larval tick can survive up to eight months without a blood meal, but it will typically feed on a small mammal, like the white-footed field mouse, as its first blood meal (Kocan, et al., 2015). 90% of larval deer ticks in northern regions of the United States will feed on a mouse that is infected with Lyme, and become a carrier of the bacterium (Simon, et al., 2014).

To translate Lyme risks internationally and domestically, it is important to understand why the risk is posed to populations it has not been before (Greig, et al., 2018). All regions are experiencing climate change differently. There is a large gap in knowledge between people living in rural and urban areas,

where the highest risk is to those living in rural areas but the risk is increasing in urban areas where the minimum temperatures are increasing year round (Eddens, et al., 2019).

From tick ecology to public health practice; conclusion

The data support a need for an increase in public outreach, as well as for healthcare professionals to improve communication of the risks and signs of Lyme disease to their patients. This can be done through specialized Lyme programs during the warmer months when Lyme is at the highest risk, as well as maintaining clear information and communication with the community all year long, including graphics of what symptoms might look like, or how the typical rash could present on all skin types (O'Mara-Eves, et al., 2015). To close this gap, rural communities such as those in Crawford County can utilize public health strategies to decrease cases of Lyme. There are opportunities to create sites to drop ticks off to be tested to ease the confusion of mailing a tick, increase patient-provider communication on the risks and symptoms of Lyme, and encourage the importance of preventative behaviors (Bouchard, et al., 2018). Increased insecticide treatment in high-traffic public areas can be beneficial to humans and animals, as well as minimizing the number of ticks able to survive in the area.

In the context of Crawford County, there is a prevailing assumption that only individuals spending prolonged periods outdoors are at risk of contracting Lyme. However, the reality is that the risk of exposure is equally high in residential areas as it is in the woods due to the prevalence of ticks in the area (Eddens, et al., 2019). This assumption perpetuates a lack of information provided by medical and public health professionals and shifts attention towards individuals who hunt, play outdoor sports, or frequent wooded areas. To effectively improve risk communication, it is essential to extend awareness to all residents, regardless of their outdoor activity, by relaying information about general tick presence in the area and the periods of increased tick activity

With global and public health goals in sight, it is important to closely monitor the translation of clear and accurate information to the general public, particularly when gathering data based on participants' levels

of knowledge. It is a public health responsibility to explore the areas of Lyme disease that are not comprehended by general populations, as well as communicate methods of prevention and local resources that are available to those affected (Monaghan, et al., 2015).

Public health professionals cannot stop climate change, but efforts can be made to mitigate the risks of emerging diseases and other health threats to humans through community engagement programs and communication of consequences (O'Mara-Eves, et al., 2015). Informing residents of the region's ongoing research efforts and communicating both the risks and symptoms associated with the onset of Lyme, as well as the potential progression of the disease when left undiagnosed, will strengthen the success of future Lyme interventions. Throughout this project, feedback from participants and the general public demonstrated a genuine interest in understanding Lyme disease and a positive attitude toward learning about the disease and its prevention methods.

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Appendix I

Survey Questions

Required: Over age 18? Y/N

1. How likely are you to get Lyme disease? *1 (not likely at all) - 5 (very likely)*
2. Do you have an indoor pet that goes outside? *Y/N*
3. How can you best protect yourself against Lyme? *Select one.*
    - Wearing boots and dark clothing, checking my body for ticks when I get home
    - Wearing tall socks tucked into long pants, and long-sleeved shirts, using bug spray containing DEET, and checking myself for ticks when I get home
    - Wearing short sleeves, long pants, and boots, and using all-natural bug spray, and checking myself for ticks when I get home
4. Were you (or anyone living with you) diagnosed with Lyme in the past year? *Y/N*

    *This includes pets or humans
5. How do *you* prevent or reduce your risk of Lyme? *(short-answer)*
6. Do you think more could be done to inform people about the risk of an increasing number of ticks in the area? *Y/N*
7. From whom would you want to hear more information about Lyme Disease? *Select one.*
    - Medical professionals
    - local government (county) representatives
    - individual town representatives
    - self-accessible information
8. Have you heard of the trial Lyme Disease vaccine? *Y/N*
9. In general, please rate how likely you are to get vaccinated against Lyme disease.

    1 (completely against) - 5 (plan to get vaccinated if able)