AMCARF Project Status Report

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Report Type: No-Cost Extension Final Report

Project Title: Analysis of perceived risks and benefits of mosquito abatement and personal protection strategies

AMCARF project number: 2023-01

Project Cost: $27,665.00

No-Cost Extension Period: December 31, 2024, to May 30, 2026

Project Leader: Emily Mader, Senior Extension Associate, Cornell University Department of Entomology

Collaborators: *Updated to reflect team during no-cost extension period*

LAST NAME, FIRST NAME	POSITION, AFFILIATION	Percent Effort
Harrington, Laura	Professor, Cornell University Department of Entomology	0.5%
Feng, Yiwei	Graduate Student, Cornell University	100%
Mader, Emily	Extension Associate, Cornell University	25%
Greiner Safi, Amelia	Professor of Practice, Cornell University Department of Public and Ecosystem Health	10%

Project Objectives – *No-cost Extension Period*:

1. We received approval to shift our focus to tickborne diseases during the no-cost extension period.
2. Utilize a focus group approach to understand risk perceptions and communication needs regarding Lyme disease exposure and tickborne disease prevention, strategy benefit perceptions, and motivators of self-efficacy across rural communities in 4 northeastern states. *This project is primarily funded through the Northeast Regional Center for Excellence in Vector-Borne Diseases.* ***AMCA-RF project funds supported graduate student staff efforts.***
    a. Objective working targets included: 1) development of focus group discussion guide informed by public health stakeholders and theories of behavior change, 2) obtain IRB approval of focus group protocol, 3) recruit participants for focus groups, engaging audiences in rural communities in 4 northeastern states, and 4) obtain audio recordings of focus group discussions and transcribe for analysis.
3. Determine optimal ways to disseminate messaging and enhance community engagement on tick bite and tickborne disease prevention, based on the major concepts identified through focus group data analysis.
    a. Objective working targets include: 1) analysis of focus group transcript data to identify common and unique themes across participating communities and 2) finalization of conclusions and drafting a manuscript for publication and dissemination.

Total Project Progress:

Key Research Accomplishments:

- Results of the initially funded AMCA-RF project were published in the *Journal of Medical Entomology* in 2024.

  Mader EM, Clements N, Lehane A, Gangloff-Kaufmann J, Crans S, Horton C, Greiner Safi A. 2024. A qualitative analysis of perceived risks and benefits of mosquito abatement and bite prevention strategies in northeastern U.S. communities. *Journal of Medical Entomology*. tjae144. https://doi.org/10.1093/jme/tjae144

- No-Cost Extension Period
  - An IRB-approved project protocol was developed and implemented in spring and summer 2025.
  - We hosted 9 focus groups engaging 49 participants across West Virginia, New York, New Hampshire, and Maine.
  - All focus group data have been analyzed using a comprehensive and refined coding scheme.
  - A manuscript of project results is under preparation, targeted for submission to peer review in Fall 2026.

Reportable Outcomes – *No-cost Extension Period*:

A major output of this project is the development of a nuanced focus group discussion guide, which will be made available as a supplemental file to the peer-reviewed manuscript that is currently in preparation. This guide incorporates an educational intervention and is structured to gather key insights to the decision-making process around adoption of Lyme disease (LD) prevention strategies. Results of the qualitative analysis have been presented to national vector surveillance and control audiences through an oral presentation at the 2026 CDC Vector Week conference (March 2026) and 2026 virtual annual meeting for the Northeast Regional Center for Excellence in Vector-Borne Diseases (February 2026).

Through the focus group discussions, we have identified common areas of uncertainty and/or misinformation regarding tickborne disease risk, transmission, signs and symptoms, treatment, and control. We developed a resource addressing these topics, with citations to the published literature, that were shared with all focus group participants. We are working with students in the Cornell MPH program to translate parts of this document into public-facing, accessible communication tools, with a target of completion by December 2026.

Lastly, an internal report has been drafted and shared with CDC funders detailing the key code groups and associated summary narratives. This report will be referenced by the funders as they develop communication and outreach plans related to Lyme disease prevention and the Lyme disease vaccine currently under review.

Progress Assessment – *No-cost Extension Period*:

OBJECTIVE ONE

- Focus group guide development – completed March 2025
- Identification of target communities – completed between May and September 2025
- Institutional Review Board application – completed April 2025
- On-board MPH student – completed May 2025

- Focus group participant recruitment – completed September 2025
- Schedule and host focus group discussions – completed September 2025

OBJECTIVE TWO

- Transcribe focus group audio recordings – completed September 2025
- Develop and finalize code list – completed December 2025
- Independent transcript coding – completed February 2026
- Code reconciliation and summarization – completed May 2026
- Disseminate summary to stakeholders – completed May 2026
- Manuscript development – ongoing; target completion Fall 2026

Plans for the remaining funding period: Plans include drafting a report of results for peer-reviewed publication. These activities will occur after the conclusion of the funding period.

Conclusion – *No-cost Extension Period*: Findings of this qualitative investigation have identified several concepts influencing the perceived risk of tickborne diseases, willingness to engage in prevention strategies, barriers to strategy adoption, and meaningful components of communication and outreach, including trusted (and not trusted) messengers of health information.

Supporting Data:

Item A. Major Themes and Exemplary Quotes

Theme	Subtheme	Exemplar Quotations
Experiencing and addressing Lyme disease is a difficult and emotional process	Many personal stories feature a complex illness presentation or severe illness experiences	"When I had it, I probably had 25 bullseye rashes, every part of my arms, my chest, my legs, everything…but I didn't know that was a thing."
	Frustration that testing and treatment options are complex and inconsistently implemented	"The last time I had Lyme I went to the urgent care. They did not ask me. And even though I had everything except the rash at that point, they never asked me and thought I had a bladder infection."
The choice to adopt tick bite and LD prevention activities is influenced by perceptions of risk and the acceptability and accessibility of available strategies	The decision to adopt bite prevention habits is closely tied to TBD risk perceptions, particularly around perceived illness severity and treatment	"I'll say that before I had Lyme, I did not take it seriously or do any prevention or protect myself. So, it wasn't until, you know, my own first-hand experience that I, you know, learned a lot about it and was able to, I guess, protect myself moving forward."
	Some people developed a routine or 'system' to ensure they practice tick safe habits, while adoption of recommended strategies remained a challenge for others	"The hardest part is if you live alone. Right? Do you knock on your neighbor's door and say, hey, check out my back?" "My first line of defense is permethrin treated. Almo-, basically any, any, pants that I might wear outside, I make sure to treat them, yeah."

Theme	Subtheme	Exemplar Quotations
LD vaccination intentions and rationale are contextual and multifactorial, with most individuals placing stipulations on their decision-making	Vaccine uptake interest is real but conditional on safety and efficacy information	"I would need things explained to me before I got the vaccine. Like, how come people can get it multiple times without getting immunity, and yet, there can be a vaccine for it?" "I'd be interested. I wouldn't be the first one in line. Um, I'd want to see, I'd want to see some studies, I'd want to see adverse effects."
	Vaccination is viewed as an added layer of protection, not a substitution for other strategies	"But then I always feel too you don't want to have a false sense of security, because there are other diseases that the ticks transmit that and some of them are, you know, as debilitating and dangerous or more…"
	Practical barriers to vaccine access reduce interest and willingness	"For myself, having not seen a doctor in the past 5 years, uh, yeah, it's, it's kind of a pain to say, yeah, I'm gonna do a shot every year, a shot, or three of them."
Access to and interactions with the medical community on LD diagnosis and treatment add complexity to an already challenging system	Variable training and familiarity with LD and other TBDs within the medical community introduces skepticism	"Um, but a lot of people… Some doctors don't even know, they want to test you for everything else first, and by that time, you can get very sick." "Yeah, and are they on the same page? Are they privy to the same information? Do they know the standard of practice....because right now is the Wild Wild West, when it comes to Lyme and diagnosis."
	Concerns that the vaccine will make interactions with healthcare providers on LD more challenging	"But then a vaccine regarding Lyme in general would just be, I don't, my concern would be that it would muddy the waters with access to treatment, if you end up with a strain that was not addressed by the vaccine."
Communication should focus on building trust through transparency and partnership	Trust in the messenger matters as much as the message	"Well, I think an independent study done by some research university would seem trustworthy, and I think, for me personally, I think we live in a world where you've got to get information from a couple of different places." "I would be least likely to be interested in it if I heard about it from a manufacturer, like, say, Pfizer, or I can't think of Eli Lilly, you know, you see commercials, and anything that's going to feel commercialized."
	Medical providers and health authorities are not universally recognized as trusted sources	"I personally like my pharmacist. He's been very good to explain things." "Well, normally I'd say the Center for Disease Control, but I'm not sure if that's a reliable, uh, venue anymore, so I'm not really sure."
	Anecdotes and audience-specific approaches carry weight	"But I guess, like, yeah, just in thinking about communicating, I think sharing people's personal stories is really powerful, like on both sides, right?" "It's probably gonna be word of mouth, don't you think? I mean, at least among the people who are outside."

Item B. Focus Group Participant Demographic Summaries

Respondent Characteristics	Participant State of Residence n (%)				TOTAL (n=49)
	ME (n=6)	NH (n=10)	NY (n=22)	WV (n=11)	
Length of time in county of residence					
1 to 5 years	0 (0%)	2 (20%)	0 (0%)	1 (9%)	3 (6%)
6 to 10 years	1 (17%)	1 (10%)	2 (9%)	1 (9%)	5 (10%)
More than 10 years	5 (83%)	7 (70%)	20 (91%)	9 (82%)	41 (84%)
Parent/Guardian children under 14	1 (17%)	2 (20%)	3 (14%)	0 (0%)	6 (12%)
Own outdoor animals	2 (33%)	9 (90%)	11 (50%)	9 (82%)	31 (63%)
Age					
25 to 34 years old	1 (17%)	0 (0%)	1 (5%)	0 (0%)	2 (4%)
35 to 44 years old	0 (0%)	2 (20%)	4 (18%)	1 (9%)	7 (14%)
45 to 54 years old	1 (17%)	1 (10%)	3 (14%)	1 (9%)	6 (12%)
55 to 64 years old	1 (17%)	2 (20%)	4 (18%)	3 (27%)	10 (20%)
65 years old or older	3 (50%)	5 (50%)	10 (45%)	6 (55%)	24 (49%)
Yearly income					
$140,000 or more	0 (0%)	1 (10%)	7 (32%)	1 (9%)	9 (18%)
$105,000 to $139,999	1 (17%)	0 (0%)	3 (14%)	1 (9%)	5 (10%)
$70,000 to $104,999	2 (33%)	3 (30%)	4 (18%)	1 (9%)	10 (20%)
$35,000 to $69,999	1 (17%)	3 (30%)	3 (14%)	4 (36%)	11 (22%)
Less than $35,000	1 (17%)	0 (0%)	3 (14%)	1 (9%)	5 (10%)
Not Disclosed	1 (17%)	3 (30%)	2 (9%)	3 (27%)	9 (18%)
Highest education					
High school diploma or GED	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Associate degree (e.g., AA, AS)	1 (17%)	1 (10%)	1 (5%)	0 (0%)	3 (6%)
Bachelor degree (e.g., BA, BS)	2 (33%)	5 (50%)	9 (41%)	1 (9%)	17 (35%)
Master degree (e.g., MA, MS, MPH)	2 (33%)	4 (40%)	9 (41%)	8 (73%)	23 (47%)
Professional degree (e.g., MD, DDS, DVM)	0 (0%)	0 (0%)	3 (14%)	0 (0%)	3 (6%)
Doctoral degree (e.g., PhD, EdD)	1 (17%)	0 (0%)	0 (0%)	2 (18%)	3 (6%)

Item C. Common Questions Identified through Focus Group Discussions

Specific to Lyme disease:

- Who is at risk / at highest risk of contracting Lyme disease?
- Do some individuals have natural immunity or genetic factors that contribute to disease presentation?
- How can you tell if you have Lyme if you are asymptomatic?
- Why do some people experience lingering symptoms? Is the infection permanent?
- What is the accuracy and cost of diagnostic tests for Lyme?
- What is the most recent standard of care for Lyme treatment?

- How is it transmitted? Can things other than ticks spread Lyme? Can multiple tick species spread it?
- How long does it really take for Lyme to be transmitted?
- Was Lyme introduced as a bioweapon?
- Why was the previous vaccine removed from the market?

General to ticks and tickborne diseases:

- Where (locations, region) is risk highest? Participants wanted field-based data on tick infection rates.
- How likely is it that any one tick is infected?
- How do ticks get infected?
- What other diseases can be spread by ticks? Can you get more than one TBD at the same time?
- Does doxycycline work for all TBDs?
- What do I do after a tick bite? How do I remove it? When do I need to seek care?
- Does the post-exposure prophylaxis actually work? Is it just for Lyme?
- Where do ticks live? What kinds of plants or environments attract them?
- What can I do to keep the ticks out of my yard? How effective are environmental control approaches?
- What happens if a tick gets brought into the home? How long can they stay alive?
- Participants also wanted more basic information about the tick life cycle, including how many hosts a tick feeds on, how infection moves through the life cycle, and how often ticks encounter infected animals.