

## **Lyme disease prevention focus groups/interviews**

Ridgefield, Fairfield County, CT

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*12 groups held, ~20 intercept interviews, total ~200 participants\**

### **Personal Prevention**

#### *Repellent*

- Virtually no knowledge of permethrin on clothing, strong interest once described, seen as more “acceptable” than on skin, still some questions about safety (esp. for kids), few knew where to locate
- Limited use of deet-based repellent; frequently expressed concerns that it is dangerous (“worse for you than the ticks”), that it kills insects (Note: compounded by the repellent only being sold next to insecticides)
  - Reluctance to use deet-based repellents especially on children, but for adults too
  - Some comments on smell/feel of products too
- Some use of non-deet repellents, though people are rarely clear of their efficacy against ticks, various plant-based products in use
  - Seeming receptivity to use non-DEET products such as IR3535 when discussed
  - Data on efficacy isn’t clear for local health departments

#### *Protective Clothing*

- Long pants sometimes mentioned, esp. by gardeners, but otherwise rejected due to high temps. Few golfers, even, with long pants.
- Scoffing references to “pants tucked into socks”—a couple respondents said they “would go so far as to [tuck pants in socks]...”

#### *Tick Checks*

- Overall this was the most frequently employed method reported by participants
- Parents better about checking kids than themselves
- Some participants expressed concern that nymphs are too small to hope to actually notice or see, concern over the ability to find ticks in children’s hair, esp. for dark- haired kids>> some respondents mentioned that they are able to “look” for ticks by touch, esp. in hair
- Older woman referred to need to use mirror to “check places you’d rather not see”

#### *Avoidance of tick-habitat*

- Many respondents stated they simply avoid high grasses, woods as these are areas where they expect ticks
- Notion of doing tick checks/other prevention when people go “outside” could be problematic – for some “outside” meant hiking or in woods, while for others that meant gardening or any outdoor activity even in the yard
- There was concern about children going to play other people’s yards, when unknown if there was tick control
- Some parents and others expressed that have severely limited outdoor activity, even in yard.
- Assumption for some respondents that grass in full sun is generally safe from ticks
- Parents of toddlers start to become more concerned as the children move around more (compared to infants), although there is concern even for babies if allowed to roll on grass.

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### *Bathing*

- As a result of the “BLAST” campaign some participants had heard of bathing soon after coming indoors – some saw this as reasonable, but it depended on time of day.
- Some individuals, especially mothers of small children, commented that they were “lucky to get 1 shower per day,” let alone showering within 2 hours of outdoor activity, so this recommendation was seen as hard to implement.

### **Household Prevention**

#### *Acaricides*

- Some respondents were using acaricides, primarily Connecticut Tick Control (CTC) treatments that varied from 2-4 times per year, though some also mentioned having a landscaping company conduct treatment.
- Very few respondents (2) had ever heard the message that a single springtime acaricide application could markedly decrease tick populations.
- Some stated an observed efficacy of “spraying” on controlling ticks on their property, others stated that they stopped service because unsure of the efficacy.
- Barrier to acaricide use mentioned was concern about effects on well water and watershed areas, unsure what could be used safely in these areas, hard to find answers they trusted.
- Respondents had questions/concerns about environmental persistence of acaricide. Likewise, respondents were concerned that if there *isn't* environmental persistence of acaricides they wondered how it can really be effective. Some respondents wanted to understand how acaricides in interrupting the tick life cycle.
  - Several people asked how spraying could be effective if deer are coming on property and dropping ticks. Single bloodmeal per adult was not clear.
- Expense of PCO-provided service mentioned as a concern. Combined with bait boxes \$2000 to \$5000/ year (dependent on size of property)
- Issue was raised that some school districts are using perimeter acaricide spraying near schools to provide some protection; this is a district decision, not always popular.
- Once mentioned that pesticide/PCO companies have an incentive to have ticks still around, perhaps this inhibits their support of deer control

#### *Bait boxes*

- Relatively few respondents were familiar with bait boxes; there was some confusion w/ products that kill rodents when question was asked. Most respondents had not heard of the bait boxes.
- Some participants were using the bait boxes, always combined with spraying, only thru CTC. Some said they still were getting service (in July) and did not know boxes would be unavailable in future.
- Concern that all neighbors need to use to really be effective
- High cost mentioned as a barrier

#### *Other property issues*

- In general the size of properties was a concern raised when property-based control was discussed, with respondents mentioning inability to protect whole area due to cost/practicality. Some respondents understood notion of protecting primary “living” areas of the yard.

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- Some participants expressed interest in measures they could control—buying products at retail level instead of thru PCO.
- Large proportion of participants reported using some method of deer control—deer fencing or spraying plants to keep deer off. There was some confusion between spraying for ticks and spraying for deer, perhaps.

#### *Natural products (e.g. Alaska Yellow Cedar)*

Strong interest, as described. Questions would be safety, efficacy, toxicity, ease of use, preference for self-application due to expense/control. As stated by one respondent, *“Natural products would be great; bring them on.”*

#### *Rodent-targeted vaccine*

Participants were generally willing to consider this as an option, rare questions about the ecological effects—primarily respondents said they would want to know what is the efficacy, what will the cost be, but there were also several respondents who expressed skepticism that any such tool could ever be employed on a scale to make a significant difference in LD.

#### **Pets**

- Many participants report that veterinarians in area often discuss Lyme as risk to pets (esp. dogs), test for Lyme and other tick-borne diseases, provide LD vaccination for pets also.
- Treatment of pets with tick control product (e.g. Frontline) is common.
  - A few respondents expressed their concern that these products make ticks less likely to attach to pets and therefore they are only more likely to bring ticks into the home and the ticks will bite the people.
- Ticks checks often reported on animals but difficulty of finding ticks, esp. nymphs was emphasized.
- A couple respondents mentioned that people in this area don't want pets because perceive that it will increase family's exposure to ticks. [Anecdotally, we were surprised re. how few people in some groups reported having dogs or other pets.]

#### **Community Prevention**

##### *Deer*

The majority of participants expressed approval for reduction in the deer population in Fairfield County, citing not only LD concerns, but car accidents and ecological concerns (damage to ecosystem etc). Some groups raised this issue quite assertively. Some exemplary comments include:

- *“We are overrun with deer”*
- *“As long as there are deer around, we are stuck with this.”*
- *Typically we have many deer around, often more than 10, however “I’d be happy with just 2”*
- *“Yes, please” in regards to deer control.*

Most questions about deer control had to do with practical issues of implementing in populated areas, safety and cost. In a few cases discrepancies in the research regarding deer depopulation and its effect on prevalence of tickborne diseases were mentioned as a concerns surrounding depopulation efforts. Some were concerned that deer control only benefitted a limited geographic area (where the hunt was conducted) rather than everyone in the community, though this seemed to be related to the pilot nature of the deer control efforts in the past.

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### **Lyme as an “Emerging Infectious Disease”**

- Life cycle/transmission cycle of *Borrelia burgdorferi* and *Ixodes scapularis* often only “fuzzily” understood >> role of deer as bloodmeal source not reservoir for bacteria often unclear, mice/other rodents seen as ubiquitous and not possible to adequately address, limited # of bloodmeals taken by ticks not well understood.
  - Some of these questions feed into respondents’ “discounting” of the potential for various interventions to work.
- Some participants, a minority, spoke about LD as part of overall changing ecological patterns in the areas, but a larger number addressed as Lyme as an “plague” inflicted upon New England, as a problem that means that kids can’t be kids and enjoy the outdoors any longer, keeping people inside their homes and children unable to play in the leaves. It was seen as “unfair” and “something has to be done.” Newcomers to the area mentioned frustration that realtors did not explain this problem.
- Responsibility: While some participants replied that there was a strong role for personal responsibility in protecting oneself from infection, there were also many who say responsibility for LD was in the hands of government (A couple requests of “why can’t they just get rid of ticks” and from one older participant “the way that malaria and typhoid were controlled.” )
- Risk reduction: A number of respondents mentioned that “we used to do [x intervention], but I couldn’t tell if it was making a difference...,” and some degree of concern that no one method would provide significant protection and this none were chosen. Some complaints that executing household protection steps would just result in a “bubble” and kids/everyone still at risk elsewhere (leading to the idea, again, of ‘why bother?’)

### **Routes/Modes of Communication**

- Specific preferred mode of depended upon focus group. Mothers with children recommended parenting magazines, federal websites regarding breastfeeding, and pediatricians. Youth indicated school libraries, pharmacies, messages to incoming college students in the area, and a “Lyme disease fair” would be good routes of communication. Others mentioned desire for public service announcements (tv & radio) and physician offices.

### **Barriers to Seeking [and Obtaining] Health Care (after tick bite/symptoms)**

#### *Public’s Knowledge of Transmission & Symptoms*

- Respondents felt that there are many people who experience possible LD symptoms but never noticed a tick and so may not seek health care. It was expressed that many people don’t understand how small nymphal ticks are and that they may not notice them.
- Respondents mentioned that many people focus on the rash only as the initial symptoms of LD, and may not be sufficiently attuned to the other possible early symptoms of infection, or may not notice rashes in harder to see areas, so again they are missing the chance for early treatment.
  - Respondents expressed the concern that people only look for the “traditional” bull’s eye rash, rather than more variations
  - Visuals drive use of materials >> LDF materials contained variety of rash images—only option with more than bull’s-eye, so these are used by some educational programs

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- Respondents felt that message that the longer a tick is attached, the greater the risk of LD transmission is not always clear and needed to be communicated more clearly to the public.
- Comments in most groups indicated that the time lag to develop antibodies that would “test positive” was not clear, and this contributed (one aspect) to confusion and perception about the poor sensitivity of testing for LD.

*Interaction with health care providers:*

- In several groups was mentioned that many physicians/health care providers insist on a positive serology test for LD before prescribing antibiotics when a person initially seeks care after noticing symptoms or having a hx of tick bite. Was described that often the HCP will not administer presumptive initial tx while waiting for test, and respondents believed that there is confusion about the time “lag” from infection to positive serology.
  - When we explained the difference between “case definition” and clinical diagnosis some respondents said that providers state that they prefer to use the case definition.
- Respondents described their impression that some health care providers only really look for a bull’s eye rash as the diagnostic symptom and won’t accept other potential early symptoms.
- Education specific to physicians must be communicated via the CDC, IDSA and respected medical journals.

**Discussion/Recommendations:**

**For CDC:**

*Website*

- Include more specific info about acaricide use on the website itself, not just embedded in the Tick Handbook
  - More detail on professional vs. homeowner use, guidelines and information on pesticides specific to tick-borne disease (“acaricide” doesn’t mean a lot to people). Provide more “actionable” information.
- Look for ways to enhance the message that the longer a tick is attached, the greater the risk of transmission.
- Can images of additional Lyme rash presentations be made available? Lack of current images from CDC pushes local education staff to use other materials.
- Explore the ‘10-myths’ concepts developed by the Ridgefield Advocacy group for possible modification for publication on the website and in print materials.
- Consider if there are ways to better present, explain tick/LD life-cycle, as lack of understanding promotes skepticism about ecological prevention approaches
- In general, respondents suggested that when there’s an option to explain more thoroughly, do it, it would be worthwhile.

*Other*

- Explore whether “single springtime application” can even be obtained from PCO’s, and investigate options for pilot project if not
- Encourage/work with DEET producers/companies to campaign to clarify safety/toxicity of their products
- Work with CDC ecology staff to assess additional repellent active ingredients (via peer-reviewed literature) and update recommendations accordingly
  - Lack of other than DEET recommendations from CDC puts local staff in position of looking for other sources of info

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- Continue the development and testing of natural repellents. As product is marketed, information regarding toxicity, effectiveness, and cost must be highlighted. Thorough market testing/research may help prospects for success.
- Develop curriculum for clinicians that will provide education regarding LD symptoms, diagnostics and treatment.(underway)
- The new, “EID-aspect” of Lyme contributes to the “someone has to fix this”, “plague-upon-us” perspective, and may make the whole panoply of prevention actions that one has to/can take more challenging. We need to address some of the related risk perception issues with a bit more thought and sophistication.

***For Local health departments:***

- Are there people in various existing groups – schools, gardeners, etc—who could be inducted as prevention advocates?
- Consider collaboration with schools to incorporate the use of tick prevention landscape techniques for school grounds
- Many respondents mentioned the need to continue to educate legislative bodies regarding the issues of LD and solicit funds for a wider (even statewide) prevention and education campaign targeting youth and their families, other key groups.
  - Several respondents suggested that movement toward the development of a statewide campaign could encourage the use of the same prevention messages, thereby minimizing mixed and potentially confusing messages to the public.
- Collaborate with the state boards of clinicians to encourage the use of continuing education provided by the CDC (when available).

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