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U.S. public's experience with ticks and tick-borne diseases: Results from national HealthStyles surveys

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Abstract

Surveillance data indicate that tick-borne diseases (TBDs) are a substantial public health problem in the United States, yet information on the frequency of tick exposure and TBD awareness and prevention practices among the general population is limited. The objective of this study was to gain a more complete understanding of the U.S. public's experience with TBDs using data from annual, nationally representative HealthStyles surveys. There were 4728 respondents in 2009, 4050 in 2011, and 3503 in 2012. Twenty-one percent of respondents reported that a household member found a tick on his or her body during the previous year; of these, 10.1% reported consultation with a health care provider as a result. Overall, 63.7% of respondents reported that Lyme disease (LD) occurs in the area where they live, including 49.4% of respondents from the West South Central and 51.1% from the Mountain regions where LD does not occur. Conversely, in the New England and Mid-Atlantic regions where LD, anaplasmosis, and babesiosis are common, 13.9% and 20.8% of respondents, respectively, reported either that no TBDs occur in their area or that they had not heard of any of these diseases. The majority of respondents (51.2%) reported that they did not routinely take any personal prevention steps against tick bites during warm weather. Results from these surveys indicate that exposure to ticks is common and awareness of LD is widespread. Nevertheless, use of TBD prevention measures is relatively infrequent among the U.S. public, highlighting the need to better understand barriers to use of prevention measures.

Keywords

Tick-borne disease; Lyme disease; Prevention; Tick exposure

Introduction

From 2009 to 2013, over 200,000 cases of tick-borne diseases (TBDs) were reported to the Centers for Disease Control and Prevention (CDC), including cases of anaplasmosis, babesiosis, ehrlichiosis, Lyme disease (LD), Rocky Mountain spotted fever (RMSF), and tularemia (Centers for Disease Control and Prevention, 2010, 2013). LD, caused by *Borrelia*

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burgdorferi and transmitted by *Ixodes* spp. ticks, leads in number of cases with over 36,000 confirmed and probable cases reported in 2013. Several novel tick-borne pathogens recently have been found to cause human illness in the United States: *Borrelia miyamotoi*, *Ehrlichia* species Wisconsin, and Heartland virus (Krause et al., 2013; McMullan et al., 2012; Pritt et al., 2011). In addition, southern tick-associated rash illness (STARI or Masters' disease), which mimics the erythema migrans rash of early LD, is associated with the bite of the *Amblyomma americanum* tick but is of unknown etiology (Wormser et al., 2005). Diverse in their vectors, geographic distribution, and clinical manifestations, TBDs represent a substantial public health problem in the United States.

In the absence of available vaccines (Food and Drug Administration, 2002; Shen et al., 2011) or easily implemented community-wide interventions, prevention of TBDs relies heavily on the consistent use of personal prevention measures and environmental tick controls on personal property (Connally et al., 2009; Curran et al., 1993; Schulze et al., 1994, 1995; Stafford, 2004). Implementation of these measures is largely contingent upon individuals' awareness of TBD risk where they live and recreate. Information on levels of TBD awareness and use of prevention measures among the U.S. public is lacking. In addition, several other important aspects of TBDs such as frequency of tick exposure and health care seeking behavior have not been quantified. Using data from nationwide HealthStyles surveys, this study was undertaken to gain a more complete understanding of the U.S. population's experience with TBDs to guide prevention and control efforts.

Materials and methods

HealthStyles is an annual, cross-sectional, nationwide survey designed to be nationally representative based on U.S. Census Bureau demographics. Porter Novelli, a social marketing and public relations firm, has conducted the HealthStyles survey since 1995, and CDC annually licenses results from the survey post-collection. Survey questions aim to assess knowledge, attitudes, and behaviors for various health-related topics and to obtain information on self-reported diseases and conditions (Kennedy et al., 2011; Kobau et al., 2006; Polen et al., 2015). In general, HealthStyles surveys demonstrate reliability and validity, showing concordance with the Behavioral Risk Factor Surveillance System on outcome levels, trends over time, and demographic breakdowns for similar health topics (Pollard, 2007).

HealthStyles survey respondents are randomly recruited each year from a large, nationally representative panel of non-institutionalized adults aged 18 years living in the contiguous United States and the District of Columbia. The 2009 HealthStyles survey was administered via mail, and the 2011 and 2012 surveys were administered online (Porter Novelli Public Services, 2009a, 2011a, 2012a). Each survey took approximately 40 minutes to complete. The specific questions regarding awareness of, prevention measures for, and experiences with TBDs are shown in Table 1 (Porter Novelli Public Services, 2009b, 2011b, 2012b). Response data were weighted using several demographic factors to ensure representativeness according to Current Population Survey (CPS) demographic proportions and to reduce potential nonresponse bias (US Census Bureau, 2006). (See Appendix A for details on

sampling methodologies and demographic factors used for weighting in 2009, 2011, and 2012.)

For this study, reported frequencies are unweighted and reported proportions are weighted. Geographic regions are those designated by the U.S. Census Bureau (Fig. 1). Statistical analysis was conducted using IBM SPSS Statistics 21 (Armonk, NY: IBM Corp.). Analysis of 2009, 2011, and 2012 HealthStyles data was judged to be exempt from institutional review board requirements.

Results

Survey response rates were 73% (4728/6504) in 2009, 69% (4050/5864) in 2011, and 80% (3503/4371) in 2012 ($P < .0001$). For all three samples combined, 51.6% of respondents were female and 68.1% were white. Median respondent age was 51 years. Most respondents had an annual household income \leq \$50,000 (55.8%), had some college education or higher (61.4%), and were employed (59.8%). Demographic characteristics of respondents matched the CPS proportions for each year (see Appendix B).

In 2009, 934 (21.0%) of 4728 total respondents reported that a household member found a tick on his or her body during the previous year; of these, 109 (10.1%) reported that a health care provider was consulted as a result of finding a tick on a household member. Respondents living in the West North Central, East South Central, and New England regions more commonly reported tick exposure in the household (36.7%, 32.2%, and 29.8%, respectively) (Fig. 1). Of all respondents reporting tick exposure in the household, health care provider consultation was most common in the New England (17.1%), Mid-Atlantic (17.0%), and Pacific (16.7%) regions and least common in the West South Central (2.4%), East South Central (3.0%), and West North Central (5.0%) regions.

Sixty (1.3%) respondents in 2009 and 43 (0.9%) in 2012 reported having been diagnosed with LD at some time in their lives. The percentage was highest in both years among respondents in the New England (6.5% in 2009, 2.2% in 2012) and Mid-Atlantic (3.0% in 2009, 2.0% in 2012) regions. Among survey respondents in 2009 who reported past diagnoses with LD, the reported duration of antibiotic treatment was \leq 4 weeks for 39.0% of respondents, 5–8 weeks for 20.3% of respondents, and $>$ 8 weeks for 35.6% of respondents. In the 2011 survey, respondents were asked about “chronic LD”; 17 (0.5%) said they had “chronic LD” and 516 (10.5%) said they knew someone else with “chronic LD.”

When asked which TBDs occur in the area where they live, respondents’ answers varied by disease and region (Table 2). Overall, 63.7% reported that LD occurs in the area where they live. Many respondents living in regions where LD is not known to occur, such as the East South Central, Mountain, and West South Central regions, reported that the disease occurs where they live (63.6%, 51.1%, and 49.4%, respectively). Overall, 20.2% of respondents reported that RMSF occurs in their area, with highest percentages in the Mountain (48.1%) and East South Central (38.3%) regions. In the New England and Mid-Atlantic regions, areas that have a high incidence of LD as well as anaplasmosis and babesiosis, 13.9% reported that no TBDs occur in their area and 20.8% said they had not heard of any of these

diseases. Regardless of region or endemicity, few respondents reported that the following diseases occur where they live: anaplasmosis (0.9%), babesiosis (1.1%), ehrlichiosis (1.4%), STARI (2.4%), tick-borne relapsing fever (1.9%), or tularemia (1.0%).

The majority of respondents (51.2%) reported that they did not routinely take any personal prevention steps against tick bites during warm weather (Table 3). Tick check was the most commonly reported personal prevention practice, with highest levels reported in West North Central (47.9%), East South Central (43.7%), and New England (43.2%) regions. Use of repellent was reported by respondents most commonly in the West North Central (30.3%), East South Central (27.6%), and West South Central (26.5%) regions, and showering to prevent tick bites was reported most commonly in the East South Central (26.6%), South Atlantic (21.4%), and West North Central (20.5%) regions.

Regarding environmental prevention measures, 10.7% of respondents reported using chemical pesticides to reduce ticks on their properties (Table 3). Highest rates of chemical pesticide use were reported by respondents in the West South Central (22.8%), East South Central (15.6%), and South Atlantic (13.0%) regions. In contrast, 10.2% of respondents overall reported that they would not use chemical pesticides on their property; respondents from the New England (14.1%) and Pacific (14.6%) regions were more commonly averse to chemical pesticide use.

Discussion

Results from these surveys suggest that exposure to ticks is common and awareness of at least one tick-borne disease (LD) is widespread in the United States. Nevertheless, use of measures to prevent TBDs is relatively infrequent, and there appear to be important gaps regarding awareness of other, non-Lyme TBDs among the U.S. public.

Reported exposure to ticks in households exceeded 18% in nearly all areas except the Mountain and Pacific regions. In New England, our results are similar to the 28% exposure rate reported by Gould et al. (2008) for endemic areas of Connecticut. In both the New England and Mid-Atlantic regions, a substantial proportion of respondents reported seeking care after tick exposure, likely driven by awareness of greater LD risk in those areas. Interestingly, in other regions, the frequency of tick exposure appears to be inversely related to care seeking, perhaps as a result of desensitization to tick exposures in areas with an abundance of ticks. For example, respondents in the West North Central and East South Central regions reported high rates of tick exposure but the lowest proportion of seeking health care for tick exposure. The inverse was true the Mountain and Pacific regions. It should be noted, however, that consultation with a healthcare provider for tick bite alone is not generally recommended, as antibiotic prophylaxis for tick bite has been validated only for the prevention of Lyme disease in very specific circumstances (Wormser et al., 2006).

A surprisingly large proportion of respondents reported receiving more than 8 weeks of antibiotic treatment for LD. While we cannot verify this time frame or determine the type of treatment prescribed or the rationale of the respondents' providers, it should be emphasized that for early LD, which comprises the majority of LD cases, there is no scientific evidence

of clinical benefit from antibiotic treatment longer than current guidelines recommend (Kowalski et al., 2010; Wormser et al., 2003, 2006). Further, in patients with persistent symptoms and a history of LD, several controlled trials showed no benefit in prolonged antibiotic therapy (Klempner et al., 2001; Krupp et al., 2003). That many respondents reported receiving prolonged therapy is concordant with other reports of providers' non-adherence to or unfamiliarity with LD treatment guidelines (Eppes et al., 1994; Kowalski et al., 2010; Magri et al., 2002). Antimicrobial treatment for longer than guidelines recommend occurs commonly with other conditions and is not an indication that longer treatment courses are medically justified (Bratzler et al., 2005; Hecker et al., 2003; Kahan et al., 2004; Lee et al., 2014). Our results indicate that providers in LD endemic areas may benefit from education regarding the duration of therapy needed, especially in light of the risk of antibiotic-related complications and development of resistance.

The level of awareness of LD was high in all regions, especially among respondents in the New England and Mid-Atlantic regions, which account for a large proportion of reported cases (Centers for Disease Control and Prevention, 2013). This observation should be tempered, however, by the fact that 51–64% of respondents living in the East South Central, West South Central, and Mountain regions with no or very low incidences of LD reported that it occurs where they live. This misunderstanding is likely a result of widespread misinformation common on the internet (Cooper and Feder, 2004) and may result in patient requests for inappropriate diagnostic tests and treatment in these regions (Perea et al., 2014). TBD education efforts for the public and providers should take care in emphasizing the highly focal nature of TBDs, highlighting which diseases occur where and noting the possibility of travel-related cases.

Respondents in regions where RMSF occurs were somewhat familiar with the disease, but there is opportunity to increase awareness considering that the disease can become rapidly fatal if not treated promptly. In contrast, awareness of less common TBDs (anaplasmosis, babesiosis, and ehrlichiosis) was low in all regions. Fortunately, since *Anaplasma phagocytophilum*, *Babesia microti*, and *Ehrlichia* species Wisconsin are transmitted by the same *Ixodes* spp. ticks that transmit *B. burgdorferi*, those with awareness of LD who adopt prevention practices against these ticks will decrease their risk of acquiring other TBDs as well.

Despite the high numbers of tick exposures and high LD awareness reported by respondents in the New England and Mid-Atlantic regions, the proportion of respondents in these regions routinely practicing personal prevention methods is lower than what has been reported in the literature for highly endemic areas (Herrington et al., 1997; Phillips et al., 2001; Shadick et al., 1997). In addition, a lower proportion of respondents in these regions reported current use of chemical pesticides to reduce ticks on properties, and a high proportion reported that they would not consider using these pesticides when compared with other regions. However, the low levels of use of personal and environmental prevention measures reported in this study may be due to the inclusion of respondents who infrequently encounter tick habitat and therefore have little need to take precautions. Alternatively, it may suggest that even with adequate levels of knowledge and awareness, additional barriers exist among the public toward adopting prevention measures, such as knowledge of effectiveness, affordability,

accessibility, and perceptions of risk (Gould et al., 2008). Future research should determine the specific reasons why people choose not to implement certain measures. Once these barriers are understood, intensive educational interventions promoting acceptable, validated methods may increase prevention practices among the public in areas of tick-borne disease risk (Daltroy et al., 2007).

Our findings are subject to several limitations. First, all data collected in the HealthStyles surveys were self-reported, may be subject to recall bias, and could not be independently validated. Second, reporting weighted proportions allows for better accuracy in terms of the representativeness of responses to the U.S. population; however, these weighted proportions are notably discrepant from the unweighted proportions (not reported) for survey questions with a small number of responses. Third, our results do not include data for persons under 18 years of age who account for a quarter of all reported LD cases. Fourth, the census regions used for our assessments do not coincide precisely with areas of endemicity for certain TBDs and do not allow for finer-scale evaluations of TBD risk in relation to reported prevention practices or disease awareness. Further, some of the survey questions are subject to variable interpretation. For example, for the question related to TBD occurrence, the phrase, “the area where you live,” could have been interpreted by respondents to mean their region, state, county, or municipality. For the survey questions on LD diagnoses, diagnosis requirements such as physician-diagnosed LD or laboratory evidence of infection were not defined. Further, the term “chronic LD” was not defined in the survey because it is in common usage among the public, particularly on the internet; it is typically used to describe a range of conditions which may or may not be associated with *B. burgdorferi* infection; and it currently has no agreed upon clinical definition (Marques, 2008). Finally, English language literacy is required to participate in HealthStyles surveys; therefore, some individuals with low literacy in English may have been underrepresented.

These limitations notwithstanding, the HealthStyles surveys had robust sample sizes, relatively high response rates, and used post-stratification weighting to ensure representativeness to the U.S. population. These findings serve as a baseline for future, annual use of HealthStyles surveys to evaluate TBD awareness, prevention practices, self-reported tick exposures, and LD diagnoses over time, increasing the validity and reliability of the current findings. In conclusion, results from the national HealthStyles surveys contribute to a more accurate picture of the overall burden of TBDs in the United States and highlight opportunities for targeted TBD health communications as well as the need to better understand barriers to use of prevention measures by the public.

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Appendix

Appendix A. HealthStyles^a sampling & data collection methodology, 2009, 2011, 2012

	2009	2011	2012
Sampling & data collection company	Synovate Inc.	GfK (Knowledge Panel)	GfK (Knowledge Panel)
Panel sampling methodology	Opt-in panel	Panel built using probability-based random sampling (using both random-digit dial and address-based methods)	Panel built using probability-based random sampling (using both random-digit dial and address-based methods)
Survey sampling methodology	Stratified random sampling based on region, household income, population density, age, and household size	Random sampling	Random sampling
Panel of potential respondents ^b	Mail panel: ~328,000 panelists <i>ConsumerStyles</i> Response rate: 49.4% (10,587/21,420)	Online panel: ~50,000 panelists <i>ConsumerStyles</i> Response rate 55.5% (8110/14,598)	Online panel: ~50,000 panelists <i>Spring ConsumerStyles</i> Response rate 57.8% (6728/11,636)
Initial wave of consumer surveys	<i>HealthStyles</i> Version B By mail Sept.–Oct. 2009 Response rate: 72.7% (4728/6504)	<i>HealthStyles</i> summer wave Online Jul.–Aug. 2011 Response rate: 69% (4050/5865)	<i>Fall ConsumerStyles</i> Online Sept.–Oct. 2012 Response rate: 80% (3503/4371)
<i>HealthStyles</i> surveys (sent to a subsample of respondents who completed the initial wave)	Cash and/or coupon cash worth \$10; respondent entered into sweepstakes to win cash prize (first place: \$1000; second place (20 prizes): \$50)	Cash equivalent reward points worth \$10; respondent entered into monthly sweepstakes to win in-kind prize worth \$500	Cash equivalent reward points worth \$10; respondent entered into monthly sweepstakes to win in-kind prize worth \$500
Respondent incentives	Gender, age, income, race, household size	Gender, age, income, race/ethnicity, household size, education, census region, metro status, and prior Internet access	Gender, age, income, race/ethnicity, household size, education, census region, metro status, and prior Internet access
Weighting factors, designed to weight the data to match U.S. Current Population Survey (CPS) proportions			

^aHealthStyles surveys are designed and conducted by Porter Novelli, a global social marketing and public relations firm (Washington, DC).

^bRespondents are recruited whether or not they have landline phones or Internet access, and, if needed, households are provided with a laptop computer and access to the Internet to complete the surveys.

Appendix B. Respondent demographics for 2009, 2011, and 2012 HealthStyles surveys

Characteristic	HealthStyles 2009		HealthStyles 2011		HealthStyles 2012	
	Unweighted no.	Weighted %	Unweighted no.	Weighted %	Unweighted no.	Weighted %
Overall	4728	n/a	4050	n/a	3503	n/a
Sex						
Male	2271	48.5	1971	48.5	1733	48.3
Female	2457	51.5	2079	51.5	1770	51.7
Age in years						
18-34	532	30.5	734	29.9	735	29.8
35-54	2386	38.3	1678	36.6	1236	36.0
55-64	897	14.8	882	16.2	706	16.2
65	913	16.4	756	17.3	826	17.9
Race/ethnicity						
White	3050	68.9	3077	68.3	2641	67.0
Black	664	11.5	349	11.4	334	11.5
Hispanic	672	13.4	348	13.5	332	14.4
Other	342	6.2	276	6.8	196	7.1
Education						
HS or less	1406	29.8	1259	43.3	1136	41.9
Some college	1761	37.5	1295	28.6	1065	29.0
Bachelor	1522	31.8	1496	28.1	1302	29.1
Not specified	39	0.9	0	0.0	0	0.0
Income						
<\$25,000	1180	24.8	695	18.6	567	19.0
\$25-\$49,999	971	24.2	932	23.6	832	22.5
\$50-\$74,999	811	18.8	804	21.3	706	21.6
\$75,000	1766	32.2	1619	36.6	1398	36.9
Employment status						
Employed	3087	67.5	2355	55.9	1985	56.1
Not employed	1606	31.8	1695	44.1	1518	43.9
Not specified	35	0.7	0	0.0	0	0.0

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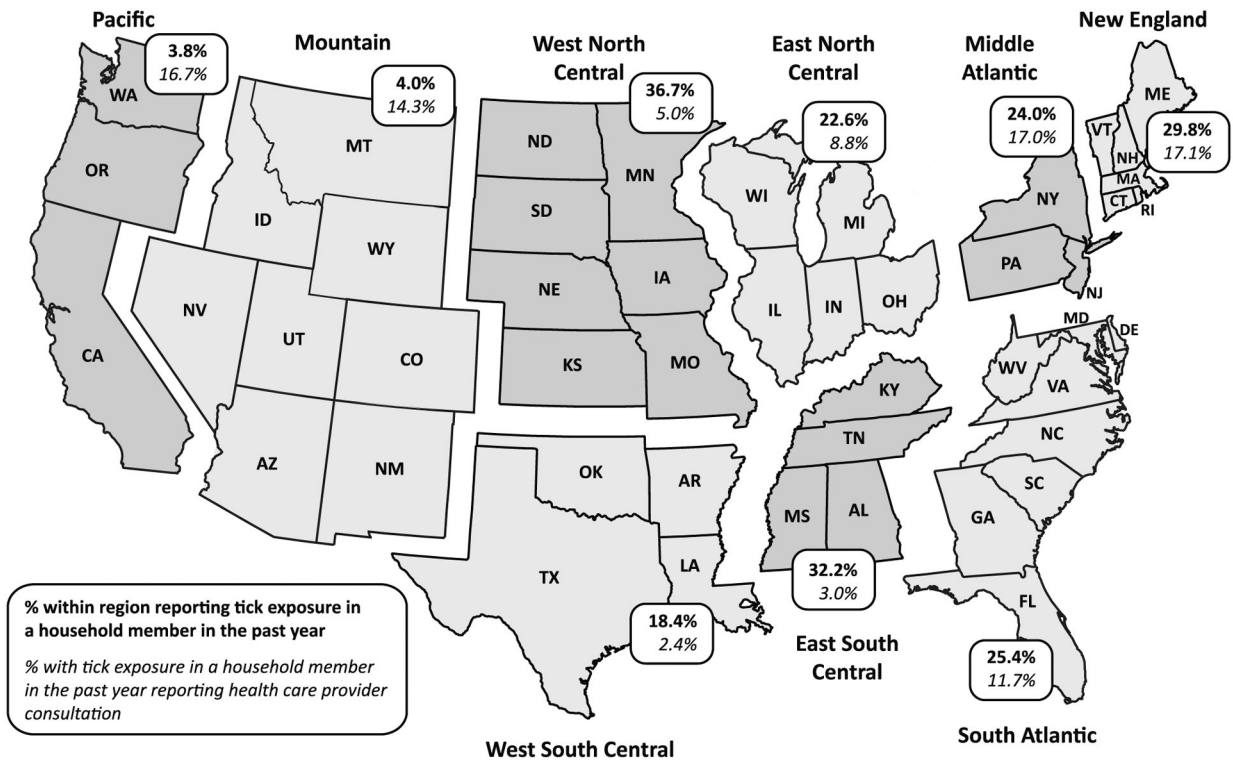


Fig. 1. Tick exposure and health care seeking by region (2009).

Table 1

HealthStyles tick-borne disease survey questions and year questions were asked.

1.	“In the last year, did anyone in your household find a tick on their body?” <i>Select one:</i> Yes; No; Not sure (2009)
2.	“If yes, did this person consult a health care provider because of finding a tick?” <i>Select one:</i> Yes; No; Not sure (2009)
3.	“Have you ever been diagnosed with Lyme disease?” <i>Select one:</i> Yes; No; Not sure (2009, 2012) ^a
4.	“If yes, how long were you treated with antibiotics?” <i>Select one:</i> 4 weeks or less; 5–8 weeks; Longer than 8 weeks; I did not receive antibiotic treatment (2009)
5.	“Do you personally know anyone who describes themselves as having chronic Lyme disease?” <i>Select all that apply:</i> Yes, I know someone; No, I do not know anyone; I suffer from chronic Lyme disease (2011)
6.	“Which of the following diseases spread by ticks occur in the area where you live?” <i>Select all that apply:</i> Lyme disease; Rocky Mountain spotted fever; Anaplasmosis; STARI or Southern Tick-Associated Rash Illness; Ehrlichiosis; Tularemia; Babesiosis; Tick-borne Relapsing Fever; None of these diseases occur in my area; I have not heard of any of these (2009)
7.	“Would you use chemical pesticides up to one or two times per year if they would meaningfully reduce the number of ticks in your yard/on your property?” <i>Select one:</i> I already use them; Yes, I would consider them; Maybe I would use them; No, I would not use them; Not sure; Don’t have a yard/land (2009)
8.	“When the weather is warm in your area, what steps, if any, do you routinely take to prevent tick bites?” <i>Select all that apply:</i> I wear repellent; I shower soon after coming indoors; I check my body for ticks when I come in; I take other steps that are not listed above; I do not take any steps to prevent ticks bites (2011)

^aIn 2012, respondents were asked, “Have you ever been diagnosed with Lyme disease?” Response options included: “No; Yes, within the past the past 6 months; Yes, 7–11 months ago; Yes, 1–2 years ago; Yes, 3–5 years ago; Yes, more than 5 years ago.” Due to a small number of responses for any of the “Yes” options, these responses were collapsed into a single “Yes” for those who reported ever having been diagnosed with LD.

Table 2

Number of respondents who believe that the indicated TBD occurs in the area where they live (2009).

Geographic region	LD <i>n</i> (% within region)	RMSF <i>n</i> (% within region)	None or “Have not heard of any of these TBDS”^a <i>n</i> (% within region)
Overall	2943 (63.7)	959 (20.2)	1559 (31.6)
New England	170 (86.1)	18 (11.5)	30 (13.9)
Mid-Atlantic	502 (78.7)	64 (7.6)	146 (20.8)
East North Central	552 (68.6)	89 (10.9)	234 (28.6)
West North Central	242 (77.9)	82 (20.6)	70 (19.3)
South Atlantic	597 (66.2)	265 (28.3)	289 (28.8)
East South Central	206 (63.6)	122 (38.3)	109 (30.2)
West South Central	242 (49.4)	110 (25.8)	236 (45.4)
Mountain	157 (51.1)	148 (48.1)	116 (30.3)
Pacific	275 (38.9)	61 (9.5)	329 (55.1)

^aThe TBDS listed in this survey question were Lyme disease, RMSF, anaplasmosis, babesiosis, ehrlichiosis, STARI, tick-borne relapsing fever, and tularemia (Table 1).

Table 3

Use of prevention measures.

Geographic region	Personal prevention measures (2011) ^a						Yard-based pesticides (2009)		
	n (% within region)						n (% within region)		
	Use repellent	Shower	Do tick checks	Other steps	Do nothing	Currently use	Would not use		
Overall	826 (21.1)	589 (15.7)	1316 (30.6)	312 (7.6)	2066 (51.2)	558 (10.7)	446 (10.2)		
New England	53 (25.6)	32 (15.1)	103 (43.2)	25 (13.1)	64 (35.9)	15 (7.2)	21 (14.1)		
Mid-Atlantic	127 (26.1)	92 (19.2)	182 (30.7)	49 (9.5)	247 (45.4)	58 (6.8)	76 (10.5)		
East North Central	152 (23.7)	81 (12.1)	219 (29.0)	44 (6.5)	336 (51.9)	60 (7.1)	83 (10.1)		
West North Central	101 (30.3)	65 (20.5)	182 (47.9)	31 (11.1)	118 (32.2)	39 (9.2)	35 (10.8)		
South Atlantic	167 (21.3)	147 (21.4)	287 (38.0)	50 (5.8)	339 (44.8)	136 (13.0)	75 (9.2)		
East South Central	54 (27.6)	49 (26.6)	86 (43.7)	25 (14.1)	63 (34.2)	50 (15.6)	25 (7.0)		
West South Central	100 (26.5)	69 (16.9)	112 (26.5)	37 (7.4)	224 (52.6)	113 (22.8)	24 (5.9)		
Mountain	34 (12.2)	18 (6.1)	64 (23.3)	14 (5.0)	216 (64.8)	24 (5.8)	33 (9.8)		
Pacific	38 (5.9)	36 (6.6)	81 (12.0)	37 (5.2)	459 (76.1)	63 (10.3)	74 (14.6)		

^a Respondents could choose more than one response.