

# Tick-Borne Disease Survey 2018

This is only a preview

To take the survey, please visit the [Climate Impact Census here](#)

## SUMMARY

Welcome to the [Climate Impact Census](#) from the [Climate Cost Project](#). This survey is about the financial burden to individuals and families from tick-borne illnesses, the spread of which has been [linked to climate change](#) and other environmental factors.

Currently, the impact and costs of tick-borne illnesses have received limited attention by researchers outside the patient/doctor communities representing patients and their families. Analyses have largely focused on healthcare system costs that exclude out of pocket spending, lost earnings, and many other costs directly experienced by patients. By taking this survey you will help provide a critical understanding of the effects of tick-borne illnesses such as Lyme disease on the American population to a broad audience.

The survey takes 15 to 30 minutes. We thank you for your participation.

## INSTRUCTIONS

**This survey can only be taken for one patient at a time.** You may take it for yourself, or for someone whose care you manage or are responsible for financially.

Please note that we understand patients' need for privacy. If you wish to take this survey anonymously, please use an anonymous email for your user login. At the end of the survey you will have the opportunity to give us your contact information if you wish to be kept updated on survey results.

**In filling out the questionnaire, you should know something about the amount of money spent—by yourself or others—on diagnosis, treatment, and care for the patient that has not been reimbursed or covered** by health insurance, government, charitable organizations, or some other entity officially recognized by the state.

For simplicity, the survey will refer to the person whose tick-borne illness is being reported as “the patient,” **including yourself if you are reporting for yourself.**

You should be 18 years or older to take this survey. It has five main parts:

1. Consent
2. Diagnoses
3. Medical costs
4. Other costs
5. Household information

All sections will appear as tabs across the top of your screen. You can navigate between sections using these tabs, or through the "Next" and "Previous" buttons at the bottom. Once you have completed the survey, select "Submit" on the final tab.

Please note that when you place your cursor on drop down answer choices you will see a "prefer not to say" option if you are not comfortable answering the question.

The Climate Impact Census uses end-to-end encryption and employs a security system which prevents unauthorized access to its databases. Please contact us at [info@climatecostproject.org](mailto:info@climatecostproject.org) if you have any concerns or questions.

## 1. Consent

Before proceeding, we first need your informed consent. By consenting, you are acknowledging that you are at least 18 years of age. You understand that your participation is voluntary and that you may withdraw at any time without penalty. You further understand that all information you provide is confidential, and no published research using data from this survey will personally identify you.

The Climate Impact Census uses end-to-end encryption and employs a security system which prevents unauthorized access to its databases. Please contact us at [info@climatecostproject.org](mailto:info@climatecostproject.org) if you have any concerns or questions.

☐

I agree to the above terms

## 2. Diagnosis

**Please note: for all questions in this survey "the patient" refers to the person for whom you are reporting costs, including yourself if you are reporting your own.**

### 1. Your relation to patient

☐

I am the patient

☐

My child is the patient

☐

My spouse or partner is the patient

☐

My parent is the patient

☐

My sibling is the patient

☐

A family member other than those above

☐

The patient is someone not directly in my family (please explain)

☐

Prefer not to say

## 2. Current infections

What tick-borne illness or illnesses does the patient currently have? Check all that apply.

- ☐ Lyme borreliosis
- ☐ Anaplasmosis
- ☐ Babesiosis
- ☐ Bartonella
- ☐ Ehrlichiosis
- ☐ Tularemia
- ☐ Rocky Mountain Spotted Fever
- ☐ Powassan virus
- ☐ Not currently sick
- ☐ Prefer not to say
- ☐ Other (please see next question)

## 3. Months sick

For how many months has the patient been symptomatic or, if he or she is in remission, was symptomatic?

## 4. PAST infections

What tick-borne illness or illnesses has the patient had in the past? Check all that apply.

- ☐ Lyme Borreliosis
- ☐ Anaplasmosis
- ☐ Babesiosis
- ☐ Bartonella
- ☐ Erlichiosis
- ☐ Tularemia
- ☐ Rocky Mountain Spotted Fever
- ☐ Powassan virus
- ☐ Not applicable
- ☐ Prefer not to say
- ☐ Don't know
- ☐ Other (see "other infections" below)

## 5. "Other" tick-borne infection

If you selected "other" in the previous question, please briefly describe what other tick-borne illness or illnesses the patient has had, or currently has.

## 6. Diagnosis method

How has the patient been diagnosed with a tick-borne illness? Check all that apply.

- ☐ Through a physical examination by a health practitioner
- ☐ Through a blood test
- ☐ Don't know or don't remember
- ☐ Presence of an erythema migrans rash
- ☐ Flu like symptoms
- ☐ Prefer not to say
- ☐ Other (please see next question)

## 7. Other means of diagnosis

If you selected "other" in the previous question, please briefly describe the diagnosis method.

## 8. Blood tests for Lyme disease

Due to the complex nature of Lyme Borreliosis, there are many ways to try to detect its presence. As such, we have additional questions for people reporting costs for patients with Lyme disease. Please tell us which of the following is true for the patient. Check all that apply.

- ☐ Positive Elisa C6 peptide test
- ☐ Positive test from California-based IGeneX lab
- ☐ Positive Polymerase Chain Reaction (PCR) test
- ☐ Positive Western Blot
- ☐ Positive culture test
- ☐ Positive antigen detection test
- ☐ Positive in one test, but I don't remember its name
- ☐ Positive in more than one test, but I don't remember all of their names
- ☐ Don't know if patient had a + blood test
- ☐ Prefer not to say
- ☐ Not applicable
- ☐ Other (please see next question)

## 9. "Other" Lyme blood test

If you selected "other" for Lyme tests, please explain here.

### 10. Western Blot tests

Some Western Blot tests for Lyme disease include analysis for outer surface proteins and related “bands” specific to the disease. Please choose the statement that best applies to the patient for any Western Blot test(s) he or she may have had.

- ☐ The patient has tested positive for one or more Lyme-specific antigens
- ☐ The patient has never been tested for any of these Lyme-specific antigens
- ☐ I don't know if the patient has ever been tested for these Lyme-specific antigens
- ☐ No applicable
- ☐ Prefer not to say

### 11. Year of first symptoms

To the best that you can remember, in what year did the patient first start having symptoms from the tick-borne illness(es)?

### 12. Other chronic illnesses

Because tick-borne illnesses are often mistaken for other illnesses, and because other illnesses can worsen the effects of a tick-borne illness and increase spending on treatment, it would be helpful to know if the patient has any other chronic physical or mental illnesses. Does the patient suffer from any other chronic illness or illnesses?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Prefer not to say

### 13. Name(s) of other illnesses

If applicable, and if you are comfortable sharing them, could you tell us what other chronic illness or illnesses from which the patient is currently suffering?

### 14. General comments

If you would like to share other information related to the patient's diagnosis or disease onset, please include that information here.

### 3. Direct Medical Costs

**Please note: for all questions in this survey "the patient" refers to the person for whom you are reporting costs, including yourself if you are reporting your own.**

There are many types of costs from tick-borne illnesses. The next few questions ask about **medical** costs. For privacy reasons, we do not ask for details on what kinds of medical care have been purchased, only total spending amounts.

You should consider both traditional Western medicine and alternative treatments. Please also include any costs incurred from having to see multiple practitioners before being correctly diagnosed, and experimentation with different treatments even if they were not successful at relieving symptoms.

Examples of medical costs:

- Health practitioner bills, such as nurses, traditional MDs, holistic providers
- Copays
- Deductibles
- Hospital or clinic visits
- Specialty foods or supplements
- Specialty equipment or devices, etc.

#### 1. Un-reimbursable medical spending, last 4 weeks

Approximately how much money was spent "out of pocket" on medical care for the patient in the last 4 weeks?

By "medical care" we mean money spent toward diagnosis, care, and treatment for the patient's tick borne illness or illnesses. By "out of pocket" we mean spending that is not reimbursed or covered by health insurance, government, charitable organizations, or some other entity officially recognized by the state.

- ☐ Less than \$100
- ☐ \$101 to \$250
- ☐ \$251 to \$500
- ☐ \$501 to \$1,000
- ☐ \$1,001 to \$2,000
- ☐ Above \$2,000
- ☐ Not applicable
- ☐ Don't know
- ☐ Prefer not to say

## 2. TOTAL out of pocket spending on medical care

Approximately how much money was spent on medical care for the patient in TOTAL since the patient first became sick with the tick-borne illness from which he or she is currently suffering, or suffered?

By "medical care" we mean money spent toward diagnosis, care, and treatment for the patient's tick-borne illness or illnesses. By "out of pocket" spending we mean spending that is not reimbursed or covered by health insurance, government, charitable organizations, or some other entity officially recognized by the state.

- ☐ Less than \$500
- ☐ \$501 to \$2,500
- ☐ \$2,501 to \$5,000
- ☐ \$5,001 to \$15,000
- ☐ \$15,001 to \$30,000
- ☐ \$30,001 to \$50,000
- ☐ \$50,001 to \$75,000
- ☐ \$75,001 to \$100,000
- ☐ \$100,001 to \$150,000
- ☐ \$150,001 to \$200,000
- ☐ More than \$200,000
- ☐ Don't know
- ☐ Prefer not to say

## 3. Date expenses began

If applicable, when did the total expenses you reported begin?

## 4. Comments: un-reimbursable medical spending

Please use the space below if you have any additional information on out of pocket spending you would like us to know about.

## 4. Other Costs

Below we ask about some of the most common costs from tick-borne illnesses other than direct medical costs, such as missed work, time spent sick at home, childcare, and missed school.

In addition to these, there are many other kinds of costs that may not be obvious to people who are not suffering from a tick borne illness. For example, a patient may be so tired that he or she decides to hire someone to mow the lawn or take care of errands

and other chores. Or a patient may give up leisure activities like camping or gardening for fear of tick bites. We are very interested in learning about these costs as well and hope you will share them in the last section where we provide a space for general comments.

Please note that all drop down answer formats include a "prefer not to say" answer choice if you are not comfortable answering a question.

### **1. Miscellaneous hardships**

Below is a list of common hardships resulting from tick-borne illnesses that can add context to personal and financial losses. If you are comfortable doing so, please check all that apply to the patient's experience.

- ☐ Bankruptcy
- ☐ Credit card debt
- ☐ Interrupted career development
- ☐ Terminated career development
- ☐ Terminated career
- ☐ Selling off of assets, e.g. a home
- ☐ Partial loss of retirement savings
- ☐ Complete loss of retirement savings
- ☐ Debt to friends, family, or others
- ☐ Terminated relationship
- ☐ None of these apply
- ☐ Other
- ☐ Prefer not to say

### **2. Comments on miscellaneous hardships**

Please feel free to share any additional information or thoughts about the patient's hardships in the comment space below.



### 3. Patient's time, last 4 weeks (Required)

If the patient has been symptomatic in the last month, please indicate approximately how much of the time, **in the last 4 weeks**, the patient felt so sick that he or she didn't participate in normal activities, such as work, school, household chores, etc., as a result of the tick-borne illness(es).

- ☐ None of the time
- ☐ Some of the time, but not more than one-third
- ☐ About one-third of the time
- ☐ About half of the time
- ☐ About two-thirds of the time
- ☐ More than two-thirds but not all the time
- ☐ All of the time
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say

### 4. Patient's time, last 365 days

If the patient has been symptomatic in the last year, please indicate approximately how much of the time, **in the last 365 days**, the patient felt so sick that he or she didn't participate in normal activities, such as work, school, household chores, etc., as a result of the tick-borne illness(es).

- ☐ None of the time
- ☐ Some of the time, but not more than one-third
- ☐ About one-third of the time
- ☐ About half of the time
- ☐ About two-thirds of the time
- ☐ More than two-thirds but not all the time
- ☐ All of the time
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say

### 5. Missed work, if applicable

If applicable, how much work has the patient missed **as a result of his or her tick borne illness(es)**? Please choose whether the amount was in days, weeks, months, or years, and enter an amount in the pop up box presented next to your choice.

- ☐ Hours (please enter a number)
- ☐ Days (please enter a number)
- ☐ Weeks (please enter a number)
- ☐ Months (please enter a number)
- ☐ Years (please enter a number)
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say

### 6. Date missed work began

If applicable, please provide the year and approximate month when the patient first started missing work as a result of his or her tick-borne illness(es).

### 7. Missed work: comments

If there is any additional information you would like to share about missed work, please use the space below.

### 8. Patient's highest earnings BEFORE becoming sick

We are interested in learning how much income a patient could have earned if he or she never became sick with the tick borne illness(es). If applicable, could you tell us approximately what the patient's **highest** annual earnings were, either through self-employment or through an employer, **before** he or she became sick with the tick borne illness or illnesses?

- ☐ Never employed before infection
- ☐ More than \$0 but less than \$9,999
- ☐ \$10,000 to \$24,999
- ☐ \$25,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$124,999
- ☐ \$125,000 to \$149,999
- ☐ \$150,000 to \$174,999
- ☐ \$175,000 to \$200,000
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say

### 9. Year of reported highest earnings

If you reported a figure for the patient's highest annual earnings in the previous question, please provide the year for which that estimate was made.

#### 10. Patient's current annual earnings

We are interested in learning whether a person may have been required to accept lower earnings as a result of being sick. For example, he or she may only be able to work part time for a lower wage rate, or not feel well enough to perform the work they could before they became sick. If applicable, could you tell us how much the patient **currently** earns from paid work, either through self employment or through an employer?

- ☐ Currently not employed
- ☐ More than \$0 but less than \$9,999
- ☐ \$10,000 to \$24,999
- ☐ \$25,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$124,999
- ☐ \$125,000 to \$149,999
- ☐ \$150,000 to \$174,999
- ☐ \$175,000 to \$200,000
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say

### 11. Decreased work hours

If the patient worked less after becoming sick, to what degree was this due to the tick-borne illness(es)?

- ☐ All of it
- ☐ Most of it
- ☐ Some of it (please explain)
- ☐ Equally with other factors (please explain)
- ☐ Only a small part of it (please explain)
- ☐ None of it
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say
- ☐ Other (please explain)

### 12. Lower compensation

Did the patient have to take a lower paying job as a result of the tick borne illness(es)?

- ☐ Yes (please explain)
- ☐ No
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say
- ☐ Other (please explain)
- ☐ Prefer not to say

**13. K-12 missed school, if applicable**

If the patient missed any school up through 12th grade, please indicate how much school was missed as a result of the tick borne illness(es). Please choose whether the amount was in days, weeks, months, or years, and enter an amount in the pop up box presented next to your choice.

- ☐ Days (please enter a number)
- ☐ Weeks (please enter a number)
- ☐ Months (please enter a number)
- ☐ Years (please enter a number)
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say
- ☐ Other (please explain)

**14. Missed school: comments**

If there is any additional information you would like to share about missed school, please use the space below.

**15. Childcare, if applicable**

If applicable, please indicate the amount of childcare, both paid and unpaid, provided to the patient as a result of the tick-borne illness(es), OR for the patient's children if the patient was too sick to care for his or her children as a result of the tick borne illness(es). Please choose whether the amount was in hours, days, weeks, months, or years, and enter an amount in the pop up box presented next to your choice.

- ☐ Hours (please enter a number)
- ☐ Days (please enter a number)
- ☐ Weeks (please enter a number)
- ☐ Months (please enter a number)
- ☐ Years (please enter a number)
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say
- ☐ Other (please explain)

#### 16. Childcare: comments

If there is any additional information you would like to share about childcare, please use the space below.

#### 17. General comments on other costs

Please share any additional information about the other costs in the previous questions, or costs not asked about above, due to the patient's illness.

## 5. Background information

**Please recall that for all questions in this survey "the patient" refers to the person for whom you are reporting costs, including yourself if you are reporting your own.** The questions in this section thus apply **to the patient** whose tick-borne illness(es) is being reported, and only to you if you are the patient.

This section asks questions about the patient's age, gender, race, and earnings. These are optional, but because they are personal, we would like to explain why they are being asked.

We also want to emphasize again that, as with the other questions in this survey, all information you provide is confidential, and no published research using data from this survey will personally identify you. However, you only need to answer questions that you feel comfortable doing so. We are happy for your participation even without answers to these questions.

These background questions are helpful to adding context to patients' experiences, and help us understand why people answering this survey might report different out of pocket expenses from one another.

**People's access to health care, and therefore how much spending they report in this survey, is related to factors such as income, health insurance coverage, and other questions in this section.** Respondents with less access to care may report less spending on this survey not because they are healthier than those reporting more spending, but **because they do not have the resources to obtain care.** By providing this information, you will help us better understand what these responses mean in terms of how people and society are actually impacted.

Please note: all drop down answer formats include a "prefer not to say" choice if you are not comfortable answering the question..

### 1. Patient gender

- ☐ Male
- ☐ Female
- ☐ Other
- ☐ Prefer not to say

### 2. Patient year of birth

### 3. Patient city

We are interested in how much tick-borne illnesses are costing families in different states and regions of the country. Could you tell us the city/town, state and zip code for the patient's primary residence?

### 4. Patient state

### 5. Patient ZIP code

### 6. Patient's health insurance

How would you characterize the patient's current health insurance?

- ☐ Excellent private coverage
- ☐ Average private coverage
- ☐ Limited private coverage
- ☐ Medicare
- ☐ Medicaid
- ☐ Both Medicare and Medicaid
- ☐ Uninsured
- ☐ Don't know
- ☐ Prefer not to say
- ☐ Other (please explain)

### 7. Patient's health insurance: additional comments

Optional

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### 8. Total number of people in patient's household

**Including the patient**, how many people live in the patient's household?

By "patient's household" we mean the patient and all individuals who live with the patient AND are related to the patient by birth, marriage, as a domestic partnership, or adoption.

- ☐ One
- ☐ Two
- ☐ Three
- ☐ Four
- ☐ Five
- ☐ Six
- ☐ Seven
- ☐ Eight
- ☐ More than eight
- ☐ Don't know
- ☐ Prefer not to say

### 9. Race / Ethnicity

Could you tell us the patient's race or ethnicity? Check all that apply.

- ☐ White or Caucasian
- ☐ Latino or Hispanic
- ☐ Black or African-American
- ☐ Middle Eastern or North African
- ☐ Asian
- ☐ American Indian
- ☐ Native Hawaiian or Pacific Islander
- ☐ Alaskan Native
- ☐ Mixed race / ethnicity
- ☐ Other
- ☐ Prefer not to say

## 10. Patient income sources

Please check all sources of income earned by the patient.

- ☐ Wage or salary income
- ☐ Pension
- ☐ Temporary assistance for needy families (TANF)
- ☐ Unemployment insurance
- ☐ Social security retirement income
- ☐ Child support
- ☐ Social security disability insurance
- ☐ Self-employed
- ☐ Don't know
- ☐ Prefer not to say

## 11. Household earnings, last 365 days

How much **combined** income did all members of the patient's HOUSEHOLD earn from work and other sources of income **in the last 365 days**?

By "patient's household" we mean the patient and all individuals who live with the patient AND are related to the patient by birth, marriage, as a domestic partnership, or adoption.

- ☐ \$0 to \$9,999
- ☐ \$10,000 to \$24,999
- ☐ \$25,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$124,999
- ☐ \$125,000 to \$149,999
- ☐ \$150,000 to \$174,999
- ☐ \$175,000 to \$200,000
- ☐ Don't know
- ☐ Not applicable
- ☐ Prefer not to say

## **12. Earnings comments**

**Please** share any additional comments about the patient's or household's earnings.

## **13. How did you hear about this survey?**

- ☐ Physician's office
- ☐ Climate Cost Project (please specify means, e.g. Facebook, Twitter, etc.)
- ☐ Friend
- ☐ Family member
- ☐ Support group
- ☐ Other (please specify)
- ☐ Don't remember
- ☐ Prefer not to say

## **14. Contact information and updates**

If you would like us to provide updates on survey results you can provide contact information below. Any personal information you provide will be kept strictly confidential and never be released or shared. If applicable, please let us know how else you might like to be involved. Check all that apply.

- ☐ It is fine to contact me for clarification
- ☐ Please email me updates as survey results are published
- ☐ I would like to provide information going forward on the patient's future expenses
- ☐ I would not like to be contacted further
- ☐ I would like to help by contacting people I know to fill out the survey

## **15. First Name**

## **16. Last Name**

## **17. Email address**

## **18. Phone (please do not use dashes)**

## **19. General comments and feedback**

If you have any further information to provide, or feedback for us, please use the space below, and then click submit to finish the survey. Thank you!