

Tick-Borne Disease Survey 2018

This is only a preview
Please click [here](#) to take the survey or [here](#) to learn more

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.

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 the patient’s diagnosis, treatment, and care 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. Diagnosis
3. Un-reimbursable medical-related expenses
4. Other costs
5. Background 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: as with other questions, all drop down answer formats include "PREFER NOT TO SAY" ANSWER CHOICES if you are not comfortable answering the question.

Please contact us at info@climatecostproject.org if you have any 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. Further, the Climate Cost Project will never share a participant's information with third parties.

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 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. Questions also include "PREFER NOT TO SAY" ANSWER CHOICES if you are not comfortable answering a question.

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 listed above is the patient (please explain)

The patient is not someone 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
- Southern Tick Associated Rash Illness (STARI)
- Not currently sick
- Prefer not to say
- Other (please see next question)

3. “Other” CURRENT infections

If you selected “other” current infection in the previous question, please briefly describe what other tick-borne illness or illnesses the patient currently has.

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
- Southern Tick Associated Rash Illness (STARI)
- Not applicable
- Prefer not to say
- Don't know
- Other (see “other past infections” below)

5. “Other” PAST infections

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

6. TOTAL months sick from tick-borne infections

How many months in TOTAL has the patient been symptomatic from tick-borne infection(s)? If symptoms are currently in remission, please report the total amount of time for which the patient was symptomatic in the past.

7. Diagnosis method

How has the patient been diagnosed with a tick-borne illness or illnesses? 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)

8. Other means of diagnosis

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

9. 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)

10. "Other" Lyme blood test

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

11. Western Blot tests

A patient can have a negative Western Blot test result even if it detects the presence of Lyme-specific antigens. If ALL Western Blots tests for the patient have been

negative, do you know if any of them indicated that the patient had Lyme-specific antigens?

- Yes, the patient had a negative Western Blot test that was positive for some Lyme-specific antigens (please list numbers of the Lyme-specific Western Blot bands for which the patient tested positive).
- Yes, the patient had a negative Western Blot test that was positive for some Lyme-specific antigens, but I do not remember the Western Blot band numbers.
- Don't know
- Not applicable, the patient had one or more positive Western Blot tests.

12. Year of first symptoms

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

13. 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

14. 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?

15. 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. Un-reimbursable Medical-Related Expenses

There are many types of costs from tick-borne illnesses. The next few questions ask about CONVENTIONAL AND ALTERNATIVE medical-related expenses on diagnosis, obtaining care, and treatments. For privacy reasons, we do not ask for details on what kinds of medical care have been purchased, only total spending amounts.

CONVENTIONAL and ALTERNATIVE medical-related expenses include:

- MDs, nurse practitioners, licensed social workers
- Co-pays and deductibles
- Holistic providers
- Hospital or clinic visits
- Home health aides for the patient
- Travel costs for obtaining care
- Specialty foods or supplements
- Specialty equipment or devices, etc.

1. Un-reimbursable medical-related expenses, LAST 4 WEEKS

Approximately how much money was spent on CONVENTIONAL AND ALTERNATIVE medical-related expenses for the patient that were NOT FULLY COVERED by health insurance, government, charitable organizations, or some other entity officially recognized by the state IN THE LAST 4 WEEKS?

- Less than \$100
- \$101 to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000
- More than \$2,000
- Not applicable because asymptomatic in the last 4 weeks
- Not applicable for a reason OTHER THAN being asymptomatic in the last 4 weeks (please explain)
- Don't know
- Prefer not to say

2. Un-reimbursable medical-related expenses, TOTAL

Approximately how much money was spent on CONVENTIONAL AND ALTERNATIVE medical-related expenses for the patient that were NOT FULLY COVERED by health insurance, government, charitable organizations, or some other entity officially recognized by the state IN TOTAL since the patient became sick with the tick-borne illness from an ongoing or resolved tick borne illness.

- Less than \$500
- \$501 to \$2,500
- \$2,501 to \$5,000
- \$5,001 to \$10,000
- \$10,001 to \$20,000
- \$20,001 to \$30,000
- \$30,001 to \$50,000
- \$50,001 to \$75,000
- \$75,001 to \$100,000
- \$100,001 to \$125,000
- \$125,001 to \$150,000
- \$150,001 to \$175,000
- \$175,001 to \$200,000
- More than \$200,000
- Not applicable
- Don't know
- Prefer not to say

3. Year unreimbursed medical-related expenses began

If applicable, to the best that you can recall, in what year did the total expenses you reported begin?

4. Unreimbursed medical-related expenses: comments

Please use the space below if you have any additional information on medical 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 medical-related expenses. In order to limit the length of the survey, we focus on some of the most common. However, we are interested in losses that may be unique to an individual patient, and hope that you will share them in the space for general comments at the end.

1. Miscellaneous hardships

Below is a list of common hardships and non-medical costs 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.

- Legally declared personal 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
- Extra childcare expenses for the PATIENT'S children
- Terminated relationship
- None of these apply
- Other
- Prefer not to say

2. Miscellaneous hardships: comments

Please feel free to share any additional information or thoughts about the patient's hardships in the comment space below including, if you wish, dollar estimates where applicable.

3. Public assistance

Did the patient receive help from any of the following programs as a result of tick-borne illness? Check all that apply.

- Unemployment insurance (see next question)
- Social security disability income (see next question)
- Food stamps (see next question)
- Temporary Assistance for Needy Families (TANF) (see next question)
- Section 8 or other housing assistance (see next question)
- Heating assistance (see next question)
- Medicare (see next question)
- Medicaid (see next question)
- Don't know
- Not applicable

- Prefer not to say
- Other (see next question)

4. Public assistance: benefit amounts

If you indicated in the previous question that public assistance was provided to the patient, please specify the weekly or monthly benefit for each benefit received, AND how long the patient has been receiving, or received, the benefit.

5. Patient's time LAST 30 DAYS

If the patient has been symptomatic in the last 30 days, approximately how many of these days was patient so sick that he or she didn't participate in regular activities for at least HALF of the day, such as work, school, household chores, etc., **as a result of the tick-borne illness(es)?**

6. 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 because the patient was asymptomatic for the last 365 days
- Not applicable for some reason OTHER than the patient being asymptomatic for the last 365 days
- Prefer not to say

7. Missed or reduced work, LAST 4 WEEKS

If applicable, how much work has the patient lost in **IN THE LAST 4 WEEKS as a result of his or her tick borne illness(es)?**

Please choose the easiest unit of time to add up the total, i.e. in hours, days, or weeks, and enter a total amount in the box presented next to your choice. The amount of missed work does not have to be consecutive. For example, if the patient lost 2 days of work one week and 3 days on another, you would report 5 days.

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

8. Missed or reduced work LAST 4 WEEKS, reason

To what degree was the LAST 4 WEEKS of missed or reduced work for the previous question **due to the tick-borne illness(es)**?

- All of it
- Most of it (please explain)
- 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)

9. TOTAL missed or reduced work

If applicable, how much work has the patient lost in TOTAL **as a result of his or her tick borne illness(es)**?

Please choose the easiest unit of time to add up the total, i.e. in hours, days, weeks, months, or years, and enter a total amount in the box presented next to your choice. The amount of missed work does not have to be consecutive. For example, if the patient lost 3 months of work one year, and two months in another year, you would report 5 months total.

- 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

10. Missed or reduced work TOTAL, reason

To what degree was the TOTAL amount of missed or reduced work for the previous question due to the tick-borne illness(es)?

- All of it
- Most of it (please explain)
- 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)

11. Date missed or reduced work began

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

12. Missed or reduced work: comments

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

13. 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?

- Not applicable; never employed before infection
- More than \$0 but less than \$5,000
- \$5,001 to \$10,000
- \$10,001 to \$25,000
- \$25,001 to \$50,000
- \$50,001 to \$75,000
- \$75,001 to \$100,000

- \$100,001 to \$125,000
- \$125,001 to \$150,000
- \$150,001 to \$175,000
- \$175,001 to \$200,000
- More than \$200,000
- Don't know
- Prefer not to say

14. 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
- Not applicable
- More than \$0 but less than \$5,000
- \$5,001 to \$10,000
- \$10,001 to \$25,000
- \$25,001 to \$50,000
- \$50,001 to \$75,000
- \$75,001 to \$100,000
- \$100,001 to \$125,000
- \$125,001 to \$150,000
- \$150,001 to \$175,000
- \$175,001 to \$200,000
- More than \$200,000
- Don't know
- Prefer not to say

15. Lower compensation

Did the patient have to accept lower compensation 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

16. Lower compensation, reason

If the patient had to take lower compensation, to what degree was this due to the tick-borne illness(es)?

- All of it
- Most of it (please explain)
- 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)

17. 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 the easiest unit of time to add up the total, i.e. in hours, days, weeks, months, or years, and enter a total amount in the box presented next to your choice. The amount of missed school does not have to be consecutive. For example, if the patient missed three months of school one year, and two months in another year, you would report 5 months total.

- 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)

18. Missed school: comments

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

20. General comments on other costs

Please share any additional information about the other costs in the previous questions, or about costs we did not ask about, 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, education, 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.

The questions are helpful to adding context to patients' experiences, and help us understand why people answering this survey might report different costs.

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.

Questions include "PREFER NOT TO SAY" ANSWER CHOICES 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

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.

9. Patient's highest level of education

What is the highest level of schooling completed by the patient?

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.

- No schooling completed

- Less than a high school diploma
- High school diploma or equivalent (for example, GED)
- Some college
- Associate degree (for example, AA, AS)
- Bachelor's degree (for example, BA, AB, BS)
- Master's degree (for example, MA, MS, MEq, MEd, MSW, MRA)
- Professional degree (for example, MD, DDS, DVM, LLB, JD)
- Don't know
- Prefer not to say

10. Patient's education: comments

Please share any additional comments about the patient's education here.

11. 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

12. 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

13. 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 \$5,000
- \$5,001 to \$10,000
- \$10,001 to \$25,000
- \$25,001 to \$50,000
- \$50,001 to \$75,000
- \$75,001 to \$100,000
- \$100,001 to \$125,000
- \$125,001 to \$150,000
- \$150,001 to \$175,000
- \$175,001 to \$200,000
- More than \$200,000
- Don't know
- Prefer not to say

14. Household earnings: comments

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

15. Highest level of education in patient's HOUSEHOLD

What is the highest level of schooling completed by all members of 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.

- No schooling completed
- Less than a high school diploma
- High school diploma or equivalent (for example, GED)

- Some college
- Associate degree (for example, AA, AS)
- Bachelor's degree (for example, BA, AB, BS)
- Master's degree (for example, MA, MS, MEq, MEd, MSW, MRA)
- Professional degree (for example, MD, DDS, DVM, LLB, JD)
- Don't know
- Prefer not to say

16. Highest level of education patient's HOUSEHOLD: comments

Please share any additional comments about household education.

17. How did you hear about this survey?

- Web search
- Physician's office
- Climate Cost Project staff
- A Facebook post (please specify)
- A Twitter post (please specify)
- An organization other than the Climate Cost Project (please specify)
- Friend
- Family member
- Support group
- Other (please specify)
- Don't remember
- Prefer not to say

18. Contact information and updates

If you would like us to provide updates on survey results you can provide contact information below. If applicable, please also let us know how else you might like to be involved.

Any personal information you provide will be kept strictly confidential and never be released or shared. 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

19. First Name

20. Last Name

21. Email address

22. Phone (please do not use dashes)

23. General comments and feedback