

CDC National Center for Emerging and Zoonotic Infectious Diseases (NCEZID) Moderator Guide for Lyme Disease Focus Groups Updated: May 13, 2025

A. Background and Privacy Policy

10 minutes

- 1. Welcome! Thank you for joining. My name is **NAME**. I'm an independent moderator with KRC Research. I will lead today's discussion.
- 2. The sole sponsor of today's discussion is the U.S. Centers for Disease Control and Prevention, or CDC. Our conversation will focus on a health topic.
- 3. I'm a professional researcher, not a CDC employee or a health expert. My role is to facilitate our conversation for the next 90 minutes. Let me tell you about it.
 - Your participation is voluntary. You do not have to answer anything you do not want to answer. You can choose to end your participation and leave the group at any time.
 - There are no wrong answers. You may have different opinions. That's OK: all of your experiences and opinions are important, and we want to hear them.
 - Since we are having this discussion online, we will need to talk one at a time and let everyone have time to speak. Not everyone has to answer each question, but it's important that everyone participates throughout this conversation.
 - If at any time you can't see the screen well or have difficulty hearing, let me know. We have a technician who can help us.
 - Please silence and put aside your cell phones.
 - If you need to step away from our discussion for any reason, you don't have to ask for my permission; just step away and come back when you are able.
- 4. Because privacy is important, I'm going to share our Privacy Policy.
 - We will protect your privacy for today's discussion, and nothing you say will be reported in association with your name. We will use first names only during the conversation. You can use a nickname or any other name you prefer.
 - Like our technician who is with us today virtually but who you do not see, a few colleagues are also with me virtually today to watch quietly and take notes.
 - We are audio and video recording the discussion. Because I am speaking with many groups like this one, it is important for me to have an accurate record. We will use the recording to make a written record, and once we have done that and the project is complete, we will destroy the recording.
 - I ask that you not share participants' identities with others outside of this group.
- 5. Does anyone have a question about what I've shared?
- 6. Does everyone agree to these policies and still want to participate?

Public reporting burden of this collection of information is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB Control Number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS H21-8, Atlanta, Georgia 30333; ATTN: PRA 0920-1154

One thing you have in common is that everyone is [A PARENT / ACTIVE OUTDOORS]. Let's introduce ourselves. Tell us...

- 7. Your first name or preferred name
- 8. Where you're located
- 9. **IF PARENT GROUP** The ages of your children and something you enjoy doing outdoors together in the warmer months
- 10. IF OUTDOORS GROUP Some activities you enjoy doing outdoors in the warmer months

11. I also understand that some of you are dog owners.

- Who here has a dog at home? SHOW OF HANDS
- For dog owners, what kind of activities do you do with your dog outdoors?
- C. Lyme Disease Awareness and Knowledge

6 minutes

Today we're going to be talking about Lyme disease. In a bit, we'll look at some materials about this topic. But first, I'd like you to tell me about Lyme disease. As a reminder, there are no right or wrong answers, we simply want to hear about your individual views, opinions, and experiences.

- 12. Who here feels familiar with Lyme disease? SHOW OF HANDS
 - Who feels unfamiliar? SHOW OF HANDS
- 13. For everyone: what first pops into your mind when you think about Lyme disease?
- 14. For everyone: what do you know about Lyme disease, or what have you heard? **PROBE FOR DETAILS**
- 15. Who has had experience with Lyme disease, personally or indirectly? (MODERATOR NOTE: Allow for detailed and emotional responses but reiterate that we are interested in hearing from everyone).
 - Briefly, what experience have you had?
- 16. How is Lyme disease spread? PROBE FOR DETAILS
 - What do you know about how people get infected with Lyme disease?
 - What needs to happen for a tick to transmit Lyme disease to a person?
 - What do you know about the ticks that carry Lyme disease?
 - Where and when do you think you're most likely to encounter those ticks?
- 17. What happens to a person when they have Lyme disease?
 - What are the symptoms?
 - How are they treated, if at all?
- 18. Who can get Lyme disease?
- 19. What puts someone at greater risk for Lyme disease?
 - What behaviors or activities?
 - What other factors? **PROBE**: pre-existing health conditions, age, weather, seasons, location?

D. Lyme Disease Perceptions and Prevention

10 minutes

I'd like everyone to give me two ratings. We'll do them one at a time, and then we'll talk about them. For now, <u>don't explain your rating</u>, just share your number.

20. First, on a 1 to 10 scale, how would you rate **[PARENTS:** your children's risk or chances] **[OUTDOORS:** your risk or chances] of contracting Lyme disease in the next few years? A "1" means extremely low risk, and a "10" means extremely high risk. **MODERATOR RECORD SCORES**

- 21. Now, on a 1 to 10 scale, how would you rate the seriousness of a Lyme disease infection on **[PARENTS:** your children's health] **[OUTDOORS:** your health]? A "1" means extremely low seriousness, and "10" means extremely high seriousness. **MODERATOR RECORD SCORES**
- 22. Let's talk about the ratings you gave for risk.
 - For those with lower scores, why did you say that?
 - For those with higher scores, why did you say that?
- 23. Let's talk about the ratings you gave for seriousness.
 - For those with lower scores, why did you say that?
 - For those with higher scores, why did you say that?
- 24. Lyme disease is contracted through the bite of infected ticks. What things can you do to protect **[PARENTS:** your children and yourself] **[OUTDOORS:** yourself] from tick bites that can cause Lyme disease?
 - **PROBE FOR SPECIFICS:** permethrin treated clothing, insect repellent, avoiding tick habitats, checking for ticks, etc.
 - i) **IF PERMITHERIN IS QUESTIONED, FIRST RE-DIRECT:** Are you aware of permethrin? Tell me what you know about it.
 - ii) **THEN, IF NEEDED:** Permethrin is an insecticide that is used to control a variety of pests, including mosquitoes and ticks. It works by disrupting the nervous system of insects, causing them to be unable to move or feed. Permethrin can be found in sprays, lotions, and treated clothing and gear.
 - Which of these preventive practices do you think are the <u>most effective</u> at preventing Lyme disease?
 - i) **PROBE:** What makes those practice(s) seem the most effective?
 - ii) Which do you think are the least effective?
- 25. Which of these preventive things do you do now? Why?
 - Which do you not do as often or at all? Why?
 - What factors make it hard or unlikely that you would do these things regularly?
- 26. Imagine you find a tick attached to your skin **[PARENTS:** or your child's skin]. What would you do first?
 - How would you remove the tick?
 - What are some other ways you've heard of removing a tick?
 - [MODERATOR RECORD ANSWERS FOR REFERENCE LATER]
- 27. What signs or symptoms, if any, would you watch for after a tick bite?
 - If symptoms appeared, what would you do next?
- 28. Before today, when have you thought about tick bites and Lyme disease, if at all? What situations?
 - PROBE: what was happening that made you think of ticks and Lyme disease?
- 29. Some people may think more about ticks and tick bite prevention in a seasonal or cyclical way. Is that true for you?
 - Help me understand <u>specifically</u> what aspects of seasonality are cues for <u>you</u> to <u>start thinking</u> <u>about tick bite prevention</u> for a new year. Is it... **SHOW ON SCREEN IF NEEDED**
 - i) The calendar flipping to a certain month?
 - ii) The temperature hitting a certain level?
 - iii) A certain type of weather, like lots of sunshine?
 - iv) Certain types of plants and vegetation growing in?
 - v) Around a certain holiday or yearly event?
 - vi) When parks and trails and outdoor spaces start opening up?
 - vii) When you start seeing news stories about bug bites?
 - viii) When you start thinking about vacations, camps, hikes, or bike rides, etc.?
 - ix) Seeing the first tick of the season?
 - x) Something else?

E. Information Sources and Sharing

Briefly, let me ask about information sources on this topic.

- 30. Where have you come across information about Lyme disease, tick bites, and tick bite prevention before? **PROBE**: Other people (whom), websites (which), news stories (which), etc.
- 31. Who or what would you trust most for good information about Lyme disease, tick bites, and tick bite prevention?
 - What about that source makes it a trustworthy source of information?
- 32. Have <u>you</u> ever shared information about Lyme disease, tick bites, and tick bite prevention with other people?
 - What did you share, and where did this information come from?
 - Did you send them outside resources, or did you tell them directly in conversation or a message?
 - On what platform or method did you share this information?
 - Whom did you share that information with, and what compelled you to share this?

33. Do you have any other questions about Lyme disease, tick bites, or tick bite prevention?

F	Concept Testing	40 minutes (~10 minutes	per concept)
	Concept resting	40 111111111111111111111111111111111111	

Now we're going to look at draft materials from CDC about Lyme disease.

We will look at four different sets of materials. We can call each set a <u>concept</u>. Each concept includes a poster and a couple social media posts that have thematically similar visuals and text.

These concepts could be used as the basis for posters, print ads, or online ads that are published in the future. But for now, these are <u>drafts;</u> they aren't final. Your feedback will help to make them better.

A few more things:

- I did not create these. Please be honest!
- I'm interested in <u>your</u> opinions, not what you think <u>others</u> might think.
- Resist the urge to compare the concepts. We'll do that later. For now, treat each one on its own.

Do you have any questions before we start?

Let's look at the first one. Again, this one concept has a poster and a couple social media posts.

SHOW FIRST CONCEPT (RANDOM ORDER). START WITH POSTER, THEN MOVE TO SOCIAL POSTS, THEN MOVE TO SUMMARY SLIDE WHERE ALL ASSETS SHOWN ON ONE SCREEN.

- 34. Please rate this entire concept on a scale from 1 to 5, where 1 means you don't like it at all, and 5 means you like it a lot. I'll get a rating from everyone. **MODERATOR RECORD SCORES**
- 35. In a few words, what's your first impression of this concept?
- 36. What do you like about this? Why? **PROBE**: What can you point to?
 - Is it interesting? Why?
- 37. What do you dislike? Why? PROBE: What can you point to?
- 38. Would this catch your attention if you were passing by or scrolling online? What can you point to?If I hadn't asked you to, would you have paused to read this in full? Why?
- 39. How would you describe the tone of this concept?
 - Does that tone feel appropriate for this subject matter?

- 40. What's the main idea or message this is communicating, in your own words?
- 41. On the whole, how clear and understandable is this concept?
 - Is anything unclear or confusing? PROBE: Words or phrases? Visuals?
 - Do you have any questions about this?
- 42. How useful is the information on this concept?
 - Is any critical information missing?
- 43. What kind of people does this feel designed for? Why?
 - Does this feel relevant for [PARENTS: you and your children] [OUTDOORS: you personally]? Why?
 - How could it be made more relevant to you, so that you would read it and even act on it?
- 44. How <u>serious</u> does Lyme disease and the risk of infection seem, from what you see? Why?
 - Do you feel at increased risk of Lyme disease from what you see here? Why or why not?
- 45. Do you feel interested or inspired to take any action based on this concept? What actions?
 - If you saw a post with this visual style and content online, would you stop and read it? Why?
 - **PROBE**: Would you repost on your social media, do more research, share with friends/family, etc.

MOVE TO SECOND CONCEPT AND REPEAT PRECEDING QUESTIONS. REPEAT FOR ALL FOUR CONCEPTS.

G. Concept Comparison

5 minutes

Now that you've seen all four concepts, it's time to compare them. I'll put some images from each concept on the screen together. Then I'll get three ratings from you. Don't tell me your reasons just yet. You can choose the same concept for more than one, or even all, of these questions if that's how you feel. There are no right or wrong answers.

SHOW SUMMARY SLIDE OF ALL CONCEPTS.

- 46. First, which concept did you like the most? MODERATOR RECORD SCORES
- 47. Next, which concept will be most memorable for you? MODERATOR RECORD SCORES
- 48. Finally, which concept gives the most <u>motivation</u> to take preventive action? **MODERATOR RECORD SCORES**
- 49. Tell me about the concepts you liked the most.
 - For those who picked [MOST COMMON CHOICE], why is that your favorite?
 - For those who picked [NEXT MOST COMMON CHOICE], why is that your favorite?
- 50. Tell me about the concepts that were most motivating.
 - For those who picked [MOST COMMON CHOICE], why is that motivating?
 - For those who picked [NEXT MOST COMMON CHOICE], why is that motivating?
- 51. After seeing all the concepts, which, if any, are you most likely to repost on your own social media?

MODERATOR TO PROBE ON ANY OTHER PREFERENCE Qs AS TIME PERMITS.

H. Standalone Message Testing

10 minutes

In our remaining time together, we'll look at a few written statements or messages about Lyme disease, tick bites, and tick bite prevention. These are things that CDC or other organizations could say about the topic as part of any concept. They could be supplemental statements or pieces of information.

I'll share them and give you a chance to read.

SHOW STATEMENTS ON SCREEN, ALLOW TIME TO READ.

- 52. What's most interesting from these messages? What stood out?
- 53. What have you learned from any of these?
- 54. What are the most useful messages or parts of messages?
- 55. Which of these messages motivates you the most to take action?
 - What about that message makes you want to act?
 - What action(s) would you take?
- 56. Do you have any questions about anything you've read?
 - **PROBE**: "Blacklegged ticks" and "deer ticks" are two names for the same tick.
 - i) Which name is more familiar to you?
 - ii) What's different about the impression you get when you hear these two names?
- 57. Do these convey the urgency and seriousness of taking action about tick bites and Lyme disease? Why or why not?
- 58. Is anything unclear, ambiguous, or even confusing? Words, phrases, concepts?
 - What could be made clearer?
 - Should anything be simplified? How so?
- 59. Earlier you mentioned that you would **[INSERT METHOD FROM Q26]** to remove a tick. How does this new information change or reaffirm your understanding?
 - **PROBE**: How would you proceed now, after reading these messages?
- 60. Is this the right amount of detail for you to be able to act with confidence? Why or why not?
 - What changes would help you feel more confident in knowing what to do?

I. Conclusion

1 minute

We've reached the end of our discussion. Thank you for your attention and your thoughtful contributions to this conversation. Before we wrap up, a final question:

61. What final advice would you give to CDC as it works to develop engaging and informative communications materials for you and others in your communities?

Thank you for your time! **MODERATOR CONCLUDES.**