
CDC Division of Vector-Borne Diseases
Discussion Guide for Outdoor Enthusiast Focus Groups on Alpha-Gal Syndrome
Updated December 14, 2023

I. Background and Moderator Introduction**10 minutes**

Welcome! Thank you for joining today's discussion. My name is **NAME**. I'm an independent researcher and moderator with KRC Research. The sole sponsor of today's focus group discussion is the Centers for Disease Control and Prevention, or CDC.

Our conversation today will focus on a health topic. I'm a professional researcher, not a CDC employee or subject matter expert on health topics. My role is to facilitate our conversation for the next 90 minutes. Let me tell you a bit about it:

- There are no wrong answers. You may have different opinions. That's fine—all your experiences and opinions are important, and we want to hear from all of you.
- Since we are having these groups 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.
- We will be showing you information on your screen to look at and respond to. If at any time you can't see the screen well or have difficulty hearing, let me know. We have a technician here who can help us.
- Please silence your cell phones and put away portable devices.
- 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 as soon as you can.

Because privacy is important, I'm going to show you our Privacy Policy. **SHOW ON SCREEN AND READ**

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 this conversation. You may choose to use a nickname or any other name you prefer.
- Your participation is voluntary. You do not have to answer anything you are uncomfortable with.
- Like our technician who is with us virtually but whom you do not see, a few colleagues are also with me virtually to watch quietly and take notes.
- We are audio and video recording today's discussion for transcribing purposes. Because we are speaking with other groups like this one, it is important for me to have an accurate record of today's conversation.
- We ask that you not share any information, comments, or participants' identities with others outside of this group.

II. Participant Introductions**5 minutes**

Let's start with introductions. The first thing to know about this group is that you're all fairly active people! With that in mind, please share with us:

- Your first or preferred name
- The state you live in
- Your favorite outdoor activity and why

III. Context Setting

5 minutes

Let's talk more about these kind of activities. From what I understand, you all are fairly involved in **HUNTING // HIKING, BACKPACKING, OR CAMPING // BEING OUTSIDE WITH YOUR DOG(S) // ACTIVITIES LIKE RUNNING, BIKING, GARDENING, OR OTHER OUTDOOR ACTIVITIES.**

- What do you like about these outdoor activities you participate in?
- I said we'd focus on a health topic. With that in mind, what are some of the things you do to stay safe and healthy outdoors when you're doing these activities? Why?
 - What precautionary things do you do?

IV. AGS Awareness and Experience

8 minutes

I'd like to focus on a very specific topic for our conversation today. We'll learn more as we go along. I'll first share the condition with you: it's alpha-gal syndrome, or AGS.

- Have you heard of alpha-gal syndrome before today? **SHOW OF HANDS**
- Alpha-gal syndrome is also called a few different names. Have you heard of any of these before? **ASK FOR EACH; SHOW OF HANDS FOR EACH**
 - Alpha-gal allergy
 - Red meat allergy or meat allergy
 - Tick bite meat allergy
- **IF AWARE OF ANY:** How familiar are you with alpha-gal syndrome, by this or any other name?
- **IF AWARE OF ANY:** What did you know about alpha-gal syndrome before today, prior to me sharing these names?
 - **IF MENTION TICKS OR RED MEAT OR ALLERGY, ASK:** Did you know about the connection to [ticks, red meat, or allergy] prior to hearing the name that referenced this?
 - One of the names is "tick bite allergy." Did you know about tick bite involvement before?
- **IF AWARE OF ANY:** What, if anything, do you know about the following topics related to alpha-gal syndrome?
 - How do you get alpha-gal syndrome?
 - What symptoms are there?
 - How serious is it?
 - How is it diagnosed? What treatments are there?
- Who's at risk for alpha-gal syndrome?
 - What kind of people?
 - Where do they live?
 - What do they do?
- What preventative measures are best? How do people protect themselves?
- Have you had any experience with alpha-gal syndrome before?
 - What happened?
 - What was it like?

V. AGS Reactions

20 minutes

I'm going to share more information about alpha-gal syndrome now. I'd like you to read this information, then we'll talk about it when you're finished. **SHARE ON SCREEN**

- Alpha-gal syndrome (AGS) is a serious, potentially life-threatening allergic condition. AGS is also

called alpha-gal allergy, red meat allergy, or tick bite meat allergy. AGS is not caused by an infection.

- *Alpha-gal is a sugar molecule found in most mammals, but not in humans. AGS reactions occur 2-6 hours after people eat mammalian meat (such as pork, beef, rabbit, lamb, venison, etc.), products made from mammals, or products that contain milk.*
- *AGS is associated with tick bites, and primarily with the bite of a lone star tick in the United States. Most reported cases of AGS in the U.S. are in the South, East, and Central regions. CDC estimates that as many as 450,000 people in the U.S. have AGS.*
- *AGS reactions can include hives or itchy rash; nausea or vomiting; heartburn or indigestion; diarrhea; cough, shortness of breath, or difficulty breathing; drop in blood pressure; swelling of the lips, throat, tongue, or eye lids; dizziness or faintness; or severe stomach pain.¹*
- *AGS is diagnosed through a detailed patient history, physical examination, and a blood test that looks for specific antibodies. A healthcare provider may also recommend allergy skin testing.*
- What are your first reactions to what you've seen here?
 - o What stands out? Why?
 - o **PROBE ON TOPIC**
- Does this seem... **IF YES TO ANY, PROBE ON WHY**
 - o Scary?
 - o Interesting?
 - o Dangerous?
 - o Noteworthy?
 - o Memorable?
- **FOR THOSE AWARE:** Does what you knew about AGS match what you're seeing here? Does anything conflict?
 - o What did you learn that's new?
- What, if anything, is unclear about AGS?
 - o Is anything confusing?
 - o **PROBE ON TOPIC**
 - Is it clear how someone gets AGS?
 - Is it clear what symptoms occur?
- What questions do you have about AGS?
 - o What do you want to know?
 - o **PROBE ON TOPIC**
- This information says that AGS is an allergic condition. It also says AGS is not caused by an infection. Talk to me about what you're understanding from this information.
 - o Does this make sense to you?
- How concerning does AGS seem to you?
 - o What about this is concerning, and why?
 - o **PROBE ON TOPIC**
 - Are there symptoms that are particularly concerning?
- You may have talked about this already, but based on this information, what kind of people need to be especially mindful of AGS?
 - o Where do they live?
 - o What activities do they do?

¹ <https://www.cdc.gov/ticks/alpha-gal/index.html>

- Do you feel like you're at higher, lower, or about average risk for AGS?
 - Why do you say that?
 - **PROBE:** Everyone here is quite active outdoors, and tick bites occur outdoors. Does that change your thinking at all?

VI. AGS Conversations and Prevention

15 minutes

- Have you ever had a conversation with a healthcare provider about this or related or similar topics?
 - **IF YES:** What topics did you talk about that seem relevant?
 - **IF YES:** What did you talk about?
 - **IF YES:** What questions did you have?
 - **IF YES:** How did that come up in conversation?
 - **IF YES:** Did you bring it up, or did the healthcare providers?
- Have you ever had a conversation with someone else—someone who's not a healthcare provider—about this or related or similar topics?
 - **IF YES:** What topics did you talk about that seem relevant?
 - **IF YES:** What did you talk about?
 - **IF YES:** What questions did you have?
 - **IF YES:** How did that come up in conversation?
 - **IF YES:** Did you bring it up, or did the healthcare providers?
- The information you read mentions blood testing and skin testing. What questions do you have about that topic?
- Where would you turn if you wanted to get tested?
 - Would you know where to go for this?
- Suppose you felt you were at risk or affected by AGS. Are there any challenges or barriers to you getting the care you need? What are they?
 - **PROBE:** proximity to care, coverage and uncertainty about testing, mistrust, etc.

Now let's talk about prevention.

- What preventative actions or protective measures seem important for AGS?
 - What's most important to consider in order to prevent it?
- What actions or measures are important to prevent tick bites prevention generally?

Here's a few other actions or measures someone could take to prevent tick bites and AGS.

- *Using EPA-registered insect repellent*
- *Performing tick checks*
- *Wearing long, loose-fitting clothing*
- *Showering within two hours of outdoor activity*
- *Avoiding brushy areas*
- *Tumble drying clothes*
- *Using Permethrin on clothing and gear*
- Which preventative actions or measures you mentioned do you currently take? Why?
 - **PROBE:** ease, effectiveness, low cost, etc.
 - Do any of these seem particularly important? Why?
- Which of these do you not take? Why?
 - Are there challenges involved? What are they?
 - **PROBE:** unawareness, difficulty, time-consuming, ineffectiveness, skepticism, high cost,

- etc.
- o Do any of these seem unimportant? Why?
- Which of these seem like actions or measures you'd be most likely to take in the future? Why?
 - o What would you need to see or to know in order to do some of the other actions?

Since AGS is an allergic condition, it may mean that people with AGS are prevented from eating red meat.

- Does this make you any more or less likely to take protective measures for AGS? Why?
- Does this cause you to think any differently about ticks and risks from ticks?
- Does this cause you to think any differently about your outdoor activities? How?

Likewise, AGS may mean some people are prevented from consuming dairy products and some products with alpha-gal, including some medical products.

- Does this make you any more or less likely to take protective measures for AGS or ticks? Why?

VII. AGS Information Needs and Sources

10 minutes

- You've shared some of your questions with me, and some potential points of confusion. With that in mind, what information would you most like to have to address those points?
- What resources would you most like to have on this subject?
- Where would you like this information or these resources to come from?

I'd like to briefly talk about information sources for AGS.

- First, where have you learned about AGS prior to today's discussion?
- Have you ever looked up information about AGS before? Where?
- Now, suppose you wanted to know more about AGS or get resources in the future. Where would you turn? Why?
 - o **PROBE:** people you'd talk to, specific platforms, portals, sites, etc.
 - o **PROBE:** outdoor stores, like Cabela's, REI, Bass Pro Shops, etc.
- What sources would you trust most for information on AGS? Why are they trustworthy?
 - o Which sources would you want to hear from on this? Which would you not?

VIII. AGS Messages and Testing

15 minutes

In the final part of our conversation, we'll be looking at some messages about AGS that CDC might communicate. These are draft messages; they're not finalized yet. In a moment, I'm going to share them on the screen and ask you to read them silently. Once everyone has had a chance to read, we'll talk about them together. We'll do this a few times to review a few messages.

SHARE HEADLINE & COPY AND ASK QS BELOW.

- What's your reaction to what you've read?
- What stands out about this? Can you point to anything specific?
 - o What do you like about this? What words, phrases, or ideas?
 - o What don't you like?
- How clear is this message?
 - o Is there anything you don't quite understand? What?
 - o Is there anything in the wording or language choice that's confusing or awkward? Why?

- What is main point of this message?
- Does this seem relevant for you personally? How so?
 - o **IF NO:** Who are these messages relevant for?
- What questions do you have about this message?

NEXT, SHARE EACH OF THE SIX BULLETED MESSAGES AND REPEAT QS ABOVE FOR EACH.

FINALLY, SHOW ALL STIMULI TOGETHER AND ASK QS BELOW.

Now that you've reviewed all this, I'll share it together in one place.

- Given all that you've read here, what message or part of a message...
 - o Is most useful for you to know or read?
 - o Is most memorable?
 - o Is best at conveying the seriousness of the topic?
 - o Feels most urgent?
- In your own words, what would you say is the most important thing to take away from these messages? Why? Where does that come across in the messages?
- Is there any other information you'd want to see in a message on this subject that would make you more likely to talk to your healthcare provider about preventing tick bites?

Much earlier, I gave four names that are sometimes used to describe this condition: alpha-gal syndrome, alpha-gal allergy, red meat allergy, tick bite meat allergy.

- Which of these do you prefer, and why?
- Does any one of these seem more...
 - o Clear
 - o Descriptive
 - o Serious
 - o Memorable
- AGS could be described as a syndrome, a condition, or an allergy. Tell me about the difference in those words to you.
 - o Are there advantages or drawbacks to any of these?
 - o What do each of these words suggest to you?

IX. Wrap Up

2 minutes

Thanks for all your thoughtful comments. We are going to wrap up. As we do, just a couple of closing questions.

- What would need to happen, or what would you need to see, for you to take preventative actions to stay safe from AGS?
- What advice would you give to CDC as it continues to work toward building awareness of AGS among people who are active outdoors like you?

Thank you again for your time.

MODERATOR TO DISMISS