
CDC Division of Vector-Borne Diseases
Discussion Guide for Provider Interviews on Alpha-Gal Syndrome
Updated: December 14, 2023

I. Background and Moderator Introduction

5 minutes

Welcome! My name is **NAME**. I'm an independent researcher and moderator with KRC Research. The sole sponsor of today's 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 60 minutes.

There are no wrong answers, I am simply interested in your honest opinion. However, if you feel uncomfortable answering a particular question, you do not have to.

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.
- We are audio and video recording today's discussion for transcribing purposes. Because I am leading several interviews, it is important for me to have an accurate record of today's conversation.
- We ask that you not share any information with others outside of this group.

II. Participant Introductions

5 minutes

Let's start with introductions. Can you share:

- Your first or preferred name
- A little about your specialty
- Where you practice medicine

To get started, I'd like for you to briefly tell me about your patient population.

- What kinds of patients do you see?
 - o Are many of your patients active outdoors? Doing what occupations or activities?

III. 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?
- Alpha-gal syndrome is also called a few different names. Have you heard of any of these before?
ASK FOR EACH:

Public reporting burden of this collection of information is estimated to average 60 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

- o Alpha-gal allergy
- o Red meat allergy or meat allergy
- o Tick bite meat allergy
- **IF AWARE OF ANY:** How familiar are you with alpha-gal syndrome, by this or any other names?
- **IF AWARE OF ANY:** What did you know about alpha-gal syndrome before today, prior to me sharing these names?
 - o **IF MENTION TICKS OR RED MEAT OR ALLERGY, ASK:** Did you know that prior to hearing the name that referenced this?
 - o One of the names is “tick bite meat 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?
 - o How is it contracted?
 - o What symptoms exist?
 - o How serious is it?
 - o How is it diagnosed?
 - o What treatment exists?
- Who's at risk for alpha-gal syndrome?
 - o What kind of people?
 - o Where do they live?
 - o What do they do?
 - o Is your patient population at risk? Which kind of patients?
- What preventative measures are best? How do people protect themselves?
- Have you had any experience with alpha-gal syndrome in your career?
 - o Have you seen or diagnosed alpha-gal syndrome before?
 - o What happened?
 - o What was it like?

IV. AGS Reactions

10 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*

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

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?
- **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 questions do you have about AGS?
 - o What do you want to know?
- What, if anything, is unclear about AGS?
 - o Is anything confusing?
- How concerning does AGS seem to you?
 - o What about this is concerning, and why?
 - o How concerning does it seem for your patient population in particular?
- 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 do they do?
 - o Is your patient population at risk? Which kind of patients?

V. AGS Conversations and Patient Interactions

12 minutes

- Does AGS ever come up in conversation with patients?
 - o What about topics related to AGS?
 - o **IF YES:** When has it come up?
 - o **IF YES:** What do you talk about?
 - o **IF YES:** What questions do patients have?
 - o **IF YES:** How equipped to you feel to answer patient questions on this topic?
- Does AGS ever come up in conversation with medical colleagues?
 - o Tell me about that.
- The information you read mentions blood testing and skin testing. What questions do you have about that topic?
 - o What might cause you to test a patient for AGS?
 - o Have you ever tested for AGS or referred someone for testing before?
 - o Do you feel like you have a sense of what to do on AGS testing, or not so much?
 - o What tests would you use to diagnose it?
 - o How would you go about performing the tests—who would do them, and where?
- Based on what you know or what you've read here, what makes it difficult to prevent, detect, or manage AGS? Why?
- What preventative behaviors or protective measures are you aware of related to AGS?
 - o What would you recommend to a patient who was concerned about this?
- How likely are you to tell patients about AGS and to recommend protective measures? Why?
 - o What would cause you to bring this up and have that conversation? What would trigger it?
 - o What types of materials would you prefer to use to educate patients about AGS? Are there any materials you'd avoid using?

- 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 tell your patients about AGS and to recommend protective measures? Why?
 - o To what extent would this information inspire patients to take more protective measures?
 - o What other information would inspire patients to take more protective measures?

We've talked a lot about AGS, but I'm also interested in tick-borne diseases generally.

- How familiar are you with tick-borne diseases generally?
- How often do you test or diagnose them in your patient population?
- Do you recommend any preventative behaviors or measures to your patients against tick bites?
 - o Which ones?
 - o What causes you to make those recommendations?
 - o How do your patients react—or how would they react—to these kinds of recommendations? Would they follow through?

VI. AGS Information Needs and Sources

8 minutes

Thank you. Now, let's return to AGS specifically.

- 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, either for your own benefit or for your patients' benefit? **DIFFERENTIATE AS NEEDED**

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.
- What sources would you trust most for information on AGS? Why are they trustworthy?
- Tell me about CDC resources.
 - o Have you accessed any before?
 - o Have you used them? When?
 - o Are they helpful, or not so much?
 - o Is CDC a trustworthy source on this topic?
- What would motivate you to sign-up for further education about AGS, like through a webinar or CE/CME)? Why?
 - o Would you do that if it was available?

VII. AGS Messages and Testing

10 minutes

In the final part of our conversation, I'll share some messages about AGS that CDC might communicate. These are draft messages; they're not finalized yet. In a moment, I'll share the first message on the screen and give you a chance to read it, then 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 and your patient population? How so?
 - o **IF NO:** Who are these messages relevant for?
- What questions do you have about this message?

NEXT, SHARE THE SIX BULLETED MESSAGES TOGETHER AND REPEAT QS ABOVE FOR THEM TOGETHER.

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 patients 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?
 - o Which would you use with your medical colleagues?
 - o Which would you use with your patients? Why?
- Are there certain connotations to any of these that you think are helpful? Why?
 - o Are there any connotations that are unhelpful? Why?
- Does any one of these seem more...
 - o Accurate
 - o Descriptive
 - o Urgent
 - o Serious
- 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?

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 have more conversations with patients about preventing AGS?
- What advice would you give to CDC as it continues to work toward building awareness of AGS among healthcare providers and the public?

Thank you again for your time.

MODERATOR TO DISMISS