

The Centers for Disease Control and Prevention (CDC) Asthma Communication Messaging and Materials Development: Focus Group Discussion Guide

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Project Objective: Conduct focus groups with (1) children ages 12 to 18 who are disparately affected by asthma (i.e., have visited the emergency room or had a hospital stay in the past year and have missed at least one day of school/work due to asthma) and (2) parents of children with asthma to understand the barriers and facilitators to asthma self-management.

NOTES TO REVIEWER:

This discussion guide is not a script and, therefore, will not be read verbatim. The moderator will use these questions as a roadmap and will probe as needed to maintain the natural flow of the conversation. Question probes are *italicized*.

Moderator instructions are highlighted in yellow. Materials are highlighted in blue.

Session Overview: Total Time: 90 minutes

SECTION A: Introduction and Icebreaker (5 minutes)

The interviewer will explain the purpose of the focus group, present the ground rules, and allow participants to ask any questions.

SECTION B: Asthma Background—Segment-Specific Questions (20 minutes)

The purpose of this section is to get participants warmed up and to ease them into the discussion about asthma as well as to provide context on their personal experience for subsequent discussion.

SECTION C: Asthma Attack Scenario (15 minutes)

The purpose of this section is to get a basic understanding of how participants experience a more severe asthma attack. Participants will first complete a worksheet in response to an asthma attack scenario and then discuss their responses as a group. This activity will provide insight into their action steps as well as set the tone for the next section of discussion.

SECTION D: Asthma Self-Management Barriers and Facilitators (30 minutes)

Participants will brainstorm lists and discuss in-depth barriers and facilitators to asthma self-management.

SECTION E: Asthma Messaging and Education (15 minutes)

In this section, participants will discuss sources of information for asthma management as well as the usefulness of the information, desired type and channel of information, and the ability to easily understand information.

SECTION F: Conclusion (5 minutes)

Moderator ensures that all questions are answered and all comments have been heard.

Section A. Introduction and Icebreaker (5 minutes)

Thank you for coming to talk to us today, your time is greatly appreciated. My name is _____, and I work for Fors Marsh Group, which is an independent company that conducts hundreds of focus groups like this each year. Focus groups are a type of research used to gather opinions on a specific topic. I'm here to listen to you and what you have to tell me, and it doesn't matter to me how you answer my questions, I'm interested in hearing your thoughts. Today, we would like to hear from you about how you think and feel about asthma and managing asthma. I am conducting this focus group on behalf of the Centers for Disease Control and Prevention.

We will have about 90 minutes for our discussion. Before we get started, I want to go over a few things:

- There are no wrong answers. Our whole purpose for being here is to hear what you think, so please speak up, especially if what you have to say is different than what someone else is saying. You may represent what a lot of other teens think.
- What we talk about here is confidential. This means that your individual responses will not be reported and your name will not be associated with anything you say in our reports.
- Likewise, we want to respect the privacy of everyone in this room and, therefore, ask that you please not share any of our discussions with others.
- Your participation is voluntary and you have the right to stop participating in this group at any time.
- You don't have to answer every question, but I do want to hear from everyone, so I might call on you at some point. Please speak one at a time and clearly, so I may hear you.
- You might have already noticed the glass behind me. There are people from my team who are observing and taking notes, so I can focus on our discussion. Even though other people are observing, please speak openly about your opinions and experiences. We want to learn from you, so it is important that you share your honest opinions.

- We are also audio-recording this session. I will be speaking with people across the country for this project, and it will be impossible for me to remember everything. The audio files will be transcribed, but any information that could identify you will be removed from the transcripts. At the end of our discussion, I have to write a report and will refer to the recordings and transcripts when writing the report.
- Please turn your cellphone off or switch to silent mode.
- If you need to go to the restroom during the discussion, please feel free to do so. It is [GIVE DIRECTIONS].

Does anyone have any questions before we begin?

Okay, great. First, I'm going to have everyone introduce themselves. Please tell us your name and something you like to do in your free time. I'll go first.

[Introductions and Icebreaker] It's wonderful to meet everyone—let's get started.

Section B. Asthma Background—Segment-Specific Questions (20 minutes)

[FLIP CHART]

Each of you shared that you have [asthma/a child with asthma]. I'd like to start our conversation with a brainstorming activity. I'm going to write the word asthma in the middle of the sheet here, and I want everyone to share the first words or phrases that come to mind. [Spend approximately 2-3 minutes brainstorming]

Who would like to share more about what first came to their mind? [Probe on items for approximately 2-3 minutes]

[ASK SEGMENT-SPECIFIC QUESTIONS]

CHILDREN

Now I have some general questions about your experience with asthma.

- How old were you when you were told that you had asthma?
 - *What was it like to be told that you have asthma?*
- How much do you know about asthma?
- How does having asthma make your life different than other kids' lives?
- [Show trigger stimuli] I have some pictures here of things that may cause people to have an asthma attack. What causes your asthma?
 - *What happens?*

- *How do you know you are getting an attack?*
- What does it mean to you to manage your asthma?
 - *What makes it hard to manage your asthma? What makes it easier?*
- What sort of things do you do to manage your asthma?
 - *Do you have a plan you made with your doctor to manage your asthma?*
 - *What does managing your asthma look like? [PROBE ON: Steps]*
- How important is it that you take steps to manage your asthma?
- How much, if at all, do you worry about your asthma?
- How much, if at all, do you worry about how asthma affects your life?
- Does anyone help you to manage your asthma? How so?
- How involved, if at all, are your parents in managing your asthma?
- [IF APPLICABLE] Some of you mentioned that you have had asthma for a while, when did you start to become responsible for managing your asthma by yourself?
 - *Tell me about that transition—was it difficult? Easy?*
- How often do you talk about your asthma with your parents?
 - *What do you typically discuss?*
 - **IF NO:** *Why don't you talk with your parents about your asthma?*
- How often do you talk about your asthma with your friends?
 - *What do you typically discuss?*
 - **IF NO:** *Why don't you talk with your friends about your asthma?*
- How often do you talk about your asthma with a health care provider?
 - *Who? [PROBE ON: pediatrician or other, school nurse]*
 - *What do you typically discuss?*
- How often do you talk about your asthma with your teachers or someone at school?
 - *Who? [PROBE ON: teacher, counselor]*
 - *What do you typically discuss?*

CAREGIVERS

Now I have some general questions about your experience with asthma.

- How old was your child when you were told that he or she has asthma?
 - *What it was like to be told that he or she has asthma?*
 - *How did your child take the news?*

- What circumstances led to your child being diagnosed?
- How knowledgeable would you say you are about asthma as a medical condition?
- What impact, if any, does having asthma have on your child's life?
 - *What impact does it have on your life?*
- What triggers your child's asthma?
 - *What happens when your child's asthma is triggered?*
- What does it mean to you to manage asthma?
 - *What makes it hard to manage your child's asthma? What makes it easier?*
- Who is involved in the care of your child's asthma?
- What role do you have in your child's asthma care?
 - *What sort of things do you do to help manage your child's asthma?*
- What sort of things does your child do to help manage his or her asthma?
 - *Do you have a plan you made with your child's doctor to manage your child's asthma?*
 - *What does managing your child's asthma look like? [PROBE ON: Steps]*
- [IF APPLICABLE] Some of you mentioned that your child has had asthma for a while, when did he or she start to become responsible for managing his or her own asthma?
 - *Tell me about that transition—was it difficult? Easy?*
- How important is it that your child takes steps to manage his or her asthma on his or her own?
- How much, if at all, do you worry about his or her asthma?
- How much, if at all, does your child seem to worry about his or her asthma?
- How much, if at all, do you worry about the impacts your asthma has on his or her life?
- How much, if at all, does your child seem to worry about the impacts asthma has on his or her life?
- How often do you discuss your child's asthma with your child?
 - *What do you typically discuss?*
 - **IF NO:** *Why don't you speak with your child about his or her asthma?*
- How often do you discuss your child's asthma with his or her health care provider?
 - *Who? [PROBE ON: pediatrician or other, school nurse]*

- *What do you typically discuss?*
- How often do you discuss your child’s asthma with school staff?
 - *Who?* [PROBE ON: school nurse, teacher, counselor]
 - *What do you typically discuss?*
 - IF NO: *Why don’t you speak with school staff about his or her asthma?*

Section C. Asthma Attack Scenario (15 min)

[REACTIONS WORKSHEET]

This discussion has been helpful to learn more about your experiences with asthma —it is very useful background for me as we continue talking. Next, I would like to do an activity with you. I have a worksheet that I would like for each of you to complete and then we will discuss your responses as a group. On the worksheet, you can see there is a person in the middle and three spots where you can fill in information. I am going to give you a scenario and you’ll fill in these spaces with “What you would be thinking,” “What you would be feeling,” “What you would be saying,” and “What you would be doing.”

CHILDREN: Imagine you are at school, and in the middle of class, you start to have a severe asthma attack.

CAREGIVERS: Imagine you are at home, and you notice that it appears your child is experiencing the symptoms of a severe asthma attack.

[Allow a few minutes for participants to complete worksheet]

Let’s talk about what you wrote. Who would like to share what they have written for “what you would be thinking”? [Rotate through each of the four categories, probing to understand similarities and differences among the group and underlying motivations for responses.]

Section D. Asthma Self-Management Barriers and Facilitators (30 minutes)

[FLIP CHART]

We have talked a lot about managing asthma. I’d like to do a brainstorming activity with you on the flip chart here. What are some things that might keep [you/your child] from taking steps to manage [your/his or her] asthma? Right now we’re just going to make a list so feel free to share as many ideas as you can think of. I will write down your responses and then we can talk about them.

[Participants list the items and moderator writes on chart. Allow brainstorming for approximately 2-4 minutes or until group has exhausted options. Moderator then focuses on selection of items and uses prompts as needed to fully understand idea.]

- Tell me more about [X]—how does [X] impact managing [your/your child's] asthma?
 - *In the short term?*
 - *In the long term?*
- What do you think causes [X]?
- How much is [X] a reason why [you/your child] might not take steps to manage [your/his or her] asthma at any time?
- Does anyone have a similar experience with [X]? Different?

Thinking about everything we have written in this list, what item [has the biggest impact, for you personally, on not managing your asthma/do you think has the biggest impact on your child not managing his or her asthma]? How so?

Now, I want to talk about the opposite—what helps [you/your child] to manage [your/his or her] asthma? **[IF NEEDED]**: This can be anything—tools, resources, information, people, etc.] Again, we'll make a list first and then discuss.

[Participants list the items and moderator writes on chart. Allow brainstorming for approximately 2-4 minutes or until group has exhausted options. Moderator then focuses on selection of items and uses prompts as needed to fully understand idea.]

- Tell me more about [X]—how does [X] help you manage [your/your child's] asthma?
 - *In the short term?*
 - *In the long term?*
- What do you think causes [X]?
- How much is [X] a reason why [your/your child] might take steps to manage [your/his or her] asthma at any time?
- Does anyone have a similar experience with [X]? Different?

Considering this whole list...

- How likely [are you to be able to effectively manage your asthma if you/do you think your child is able to effectively manage his or her asthma if he or she] have any of these items?
- What item [has the biggest impact for you personally in managing your/do you think has the biggest impact for you child in managing his or her] asthma?
 - *How so?*

OK, I have a few general follow-up questions to the lists we just created and the discussions we had. **[If topic has already been discussed in depth through previous discussion, please skip and/or adapt]**

- How much do you know about the different ways to manage asthma?
- What sorts of things do [you/your child] do to avoid getting an asthma attack?
 - *How well do these steps work? How often?*
- How much do you know about the different medications for asthma?
 - *How good [are you/is your child] about taking [your/their] medication?*
 - *What are some reasons [you/your child] would not take [your/their] medicine?*
 - *Are there some medications that are not available to [you/your child] because of insurance or cost?*
- How often do [you/your child] see [your/their] doctor?
- How often do [you/your child] see [your/their] doctor about [your/your child's] asthma?
 - *From who? [PROBE ON: Doctors, school nurses]*
 - *What sorts of things cause you to see a doctor about [your/your child's] asthma?*
- Do you feel like [you have/your child has] control over [your/his or her] asthma?
 - *How so? What does it mean to have control?*
- *What could help you feel more in control?* Do you think [your parent/your child] feels that [you have/he or she has] control over [your/his or her] asthma?
 - *How so?*
- How important is it that others support [you/your child] in managing [your/his or her] asthma?
 - *Does it matter who?*
 - *What type of support do they provide? [PROBE ON: parents, other family members, friends, teachers/school staff, doctors]*
- What has happened when [you have/your child has] not managed [your/his or her] asthma symptoms?
- Has missing school affected [you/your child]? How so?
 - *What other things or events [have you/has your child] missed?*
 - *Do you worry about [your child] missing school?*

- *How important is it that [you/your child] manage asthma to avoid missing school?*
- What about going to the hospital or emergency room—how has that affected [you/your child]?
 - *Do you worry about [your child] needing to visit the hospital?*
 - *How important is it that [you manage /your child manages] asthma to avoid going to the hospital?*

Section E. Asthma Messaging and Education (15 minutes)

I want to switch topics now to discuss information that you might see or hear about asthma and managing your asthma.

- Where or from whom have you received information about asthma and managing asthma ?
 - **[PROBE to understand sources—child, parents, friends, health care providers, online]**
 - *Is there somewhere that you wish had more information but doesn't?*
- What type of information have you received or seen?
 - *What did it say? / What was it about?*
- Are you seeking this information or is it being given to you?
 - *What sort of information do you look for yourself?*
- How useful has the information been?
 - *What parts were most helpful?*
 - *What parts were least helpful?*
- How well do you understand the information that you have received about asthma from the different places you mentioned?
 - **[PROBE on sources previously mentioned; e.g., child, parents, friends, health care providers, online]**
 - *What is unclear? How?*
 - *What could help make it clearer?*
- What type of information is missing that you would want to know about asthma and managing asthma?
- What would be the best way for you to get information about asthma and managing asthma?

- *Does the way you get information depend on the type of information? How so?*
- *Whom do you trust for asthma information?*
- What tools or resources would be most helpful to you?
 - How? Why?
- **FOR CHILD GROUPS:**
 - Have you ever heard about asthma from your school or in school?
 - *What type of information did you get?*
 - *How useful was it?*
 - Does anyone around you (e.g., your friends, family, school staff) need information about asthma?
 - *What sort of information would be most helpful?*
- I want you to think back to our lists on the flip board and about some of the top things that had the biggest impact on [you/your child] not managing [your/his or her] asthma—what information or resources could help address this?
 - *What would be the best way to get you this information?*
 - *When would you need this information? [IF NEEDED: During an attack? Before? After?]*
- What about the list and the top things we discussed help [you/your child] manage [your/his or her] asthma—what information would help you even more in helping these things?
 - *What would be the best way to get you this information?*
 - *When would you need this information? [IF NEEDED: During an attack? Before? After?]*
- What sort of message would motivate [you/your child] to manage [your/his or her] asthma?
 - *What would it say?*
 - *What sort of tone?*
 - *Who would it be from?*

Section F. Conclusion (5 minutes)

This has been a very helpful session. Thank you so much for taking the time out of your day to be with me and to share your perspectives and experiences. Before we

wrap up, is there anything else that you would like to share or that we might have missed?

We've talked about some things today that are sensitive, so please remember not discuss this session with others who did not attend.

[TIME PERMITTING] If you don't mind, I am going to step out for just a moment to see if my team has any additional follow-up questions for you. **[Ask any additional questions.]**

Ok, thank you again for your time. Are there any final questions? If not, you are free to go. Please leave behind your worksheets and writing utensils. Have a wonderful evening!